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Carolyn L. Bird, Ph.D., AFC - Editor In Chief TheForumJournal.org I ISSN 1540-5273 I info@theforumjournal.org

Perspectives: A Critical Anaylsis of North Carolina's On-line Central Registry for Advance Directives

Carol A. Schwab

North Carolina may be the first state to create an on-line central registry for advance directives. The law became effective January 1, 2002, and the registry is tentatively scheduled to be in service by July 2002. The registry provides an optional place to store copies of advance directives that can be relied upon as if they were originals.

The following documents, and the revocation of these documents, may be filed with the North Carolina Secretary of State for on-line registration.

- health care power of attorney
- declaration of a desire for a natural death (living will)
- > advance instruction for mental health treatment
- > declaration of an anatomical gift

Only the person who executed the document may submit it for filing in the registry. All documents, including a revocation of a document, must be notarized. The person submitting the document must supply a return address and the \$10.00 filing fee, although there is no fee for submitting a revocation of a document.

The Secretary is not required to review a submitted document to determine validity, accuracy, or compliance with statutory requirements applicable to that document. The State of North Carolina and its agents are not liable for any claims or demands arising out of the administration or operation of the registry, except for acts of gross negligence, willful misconduct, or intentional wrongdoing.

The Secretary creates a digital reproduction of the document and enters it into the registry database. The Secretary returns the original document and issues a wallet-sized card that contains a unique file number and password to the person who submitted the document. The document is accessible over the Internet only if someone has the file number and password for that document. If a person submits a revocation of a document, he or she must supply the document's file number and password to the Secretary of State, and it will be deleted from the registry database.

Registering the document does not affect its validity, nor does it create a presumption that the information contained in the document is accurate, or that the statutory requirements for the document have been met. Likewise, failure to register a document does not affect its validity. Failure to register a revocation of a registered document does not affect the validity of the revocation if it meets the statutory requirements applicable to the revocation of that document.

A health care provider may rely upon a copy of the document obtained from the registry to the same extent that the health care provider can rely upon the original document. Thus, the problem of producing the original documents can be eliminated for people who register their advance directives on-line. If a health care provider has the file number and password for a patient's advance directives, those advance directives can be obtained as needed, eliminating the delay and inconvenience of searching through a large medical file trying to find copies that cannot substitute for originals. Family members will no longer need to search through private papers or lock boxes looking for original documents. The file number and password can be prominently noted in the patient's medical file and would be as secure as the other medical information in the patient's confidential file.

Essentially, the on-line central registry is a storage option -- nothing more. The presence or absence of an advance directive in the database means nothing. A patient can have an advance directive that is not in the database. The database can contain advance directives that have been revoked. Medical providers who hoped that an on-line central registry would provide a foolproof method to determine whether a patient has an advance directive will be disappointed. On the other hand, the legislation did not create additional obstacles for health care providers who honor advance directives nor for the people who execute them.

While the legislation, at first blush, does nothing objectionable, a number of questions are raised by the legislation that may need to be clarified in the future.

First, the term "revocation of a document" as it is used in the legislation needs to be clarified. There are a number of methods for revoking an advance directive, including oral revocation. The living will is revoked when the declarant, or a representative of the declarant, has informed the attending physician of the declarant's intent to revoke. For a health care power of attorney, a revocation is not effective until the attending physician and health care agent(s) have been

notified of the revocation. So, what should be filed with the Secretary of State? The only requirements for filing a revocation of a document with the Secretary are as follows.

- > The revocation must be notarized;
- ➤ The revocation must be submitted with the document's filename and password.

The effect of filing a revocation of a document with the Secretary is merely to have the document deleted from the database. Why not call it a "Request to Delete Document from Database"? Particularly when someone may want to delete a document from the database without revoking it. The term "revocation of a document" is misleading because, unless the statutory requirements for revocation have been met, deleting the document from the database has no legal effect. Yet, use of the term "revocation," gives a casual reader the impression that an advance directive can be revoked simply by filing a "revocation" with the Secretary of State.

Second, clarification is needed about who can file a revocation of a document. The legislation is clear that only a person who executes a document can submit it for filing with the Secretary, but it says nothing about who can submit a revocation of a document. Common sense tells us that if an agent cannot submit an advance directive for filing on behalf of the principal, the agent cannot submit a revocation of the advance directive. But, common sense is not always the basis for statutory interpretation.

Third, amendments to advance directives are not addressed. What happens if a registered advance directive is amended? Under the current scheme, the declarant or principal should file a revocation, and then file the amended advance directive. Presumably, the Secretary would treat the amended advance directive as a new filing and assign it a new file number and password. The principal or declarant would have to give the new file number and password to each of his health care providers and instruct them to delete the previous file number and password. Imagine the possible confusion! Consider the following scenario.

Someone registers an amended advance directive but doesn't file a revocation for the previously registered advance directive. He fails to provide all of his health care providers with the new file number and password, so some or all of them have access to the revoked documents. Or, he notifies a health care provider of the new file number and password, but office personnel neglect to enter the new information into his medical file, keeping the outdated information. This potential confusion would be eliminated if a procedure were available for replacing registered documents with modified versions, keeping the same file number and password.

Fourth, the lag time between filing an advance directive and receiving the file number and password is not addressed. Experience will provide this information, but it is likely that several

weeks should be allotted for the process. Thus, anyone who may need the original document in the immediate future should not register it with the Secretary, unless he or she has executed multiple originals.

Fifth, the legislation is not clear whether it is limited to North Carolina residents, or if it is available to anyone. A narrow reading of the legislation supports an argument that it is limited to North Carolina documents, if not residents. The Secretary of State is mandated to "establish and maintain a statewide, on-line, central registry for advance health care directives" (emphasis added). Moreover, the list of advance directives that can be registered are referenced by North Carolina statutes.

However, if someone from Oregon wants to register an advance directive, nothing in the legislation specifically allows the Secretary to refuse registering the document. The Secretary does not examine the document for validity, accuracy, or compliance with statutory requirements, so nothing prevents the registration of an advance directive that meets the requirements of another state. With the appropriate file number and password, a health care provider in Oregon could access the registry for a copy of a patient's advance directive just as easily as a health care provider in North Carolina could. Because few states, if any, provide an on-line central registry, North Carolina may become the national database for advance directives. Particularly if the registered documents are treated as originals in other states as they are in North Carolina, giving North Carolina's registry an advantage over privately operated on-line registries.

None of these issues will create an insurmountable problem to the creation, operation, or maintenance of the registry, and all of them can be readily resolved. Overall, the legislation is drafted to minimize the concerns raised by presenters at the legislative hearings.

The biggest hurdle for the on-line central registry is consumer confidence. A <u>consumer survey</u> conducted by the author more than a year ago showed that 74 percent of respondents were "not interested at all" in registering their advance directives on-line with a state agency. The legislative committee conducted its own informal survey that showed 88 percent of respondents would be interested if they had adequate assurances about security of the system. The legislation addresses the consumer confidence issue by allowing the Secretary to use funds for the public education and awareness of the registry. The proposed public education will be funded from filing fees, gifts, donations, bequests, or other forms of voluntary contributions, or from public or private grants.

If the success of the on-line central registry depends upon consumer awareness and confidence, educators must understand that educating the lay public is only half the battle. Educating legal advisers and medical providers will also be key in the ultimate success of the registry.

Perspectives is an op-ed column. The opinions expressed in this article are the opinions of the author and do not necessarily represent the opinions of FFCI's Editorial Board, North Carolina Cooperative Extension Service, or North Carolina State University.

References

House Bill 1362, Session Law 2001-455 Chapter 130A of the General Statutes, Article 21, Section 130A-465, et seq.

Author

Carol A. Schwab, Professor and Extension Specialist, Department of 4-H Youth Development and Family & Consumer Sciences, North Carolina Cooperative Extension Service, N.C. State University.

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