

Psychiatric Advance Directives Said to Promote Patient Autonomy, Improve Care

Ever since the 1970s case of comatose patient Karen Quinlan shined light on the problem of ascertaining whether an incapacitated patient would consent to a particular medical treatment--or its withdrawal--patient advocates have sought to rationalize the law on advance instructions to health care providers. More recently, a similar movement has developed for instructions directed to psychiatric care. Today, 25 states have statutes providing for psychiatric advance directives (PADs), which ideally are prepared with provider assistance as part of discharge planning.

Introduced in the 1980s, the PAD is a legally enforceable document giving instructions on a person's behavioral health care preferences in the event he or she becomes unable to make those decision. As such, PADs should be seen as part of the larger movement toward increased patient involvement and direction in care to promote the over-arching goals of patient autonomy and dignity, according to Debra Srebnik of the University of Washington Department of Psychiatry in Seattle.

Eric B. Elbogen of the National Resource Center on PADs at Duke University in Durham, N.C., said that a well-written PAD can provide a treating physician with invaluable information about crisis symptoms and symptom escalation, including violence. This likely could help divert patients from getting admitted to hospitals, presenting them with what could be PADs' "greatest potential for hospital cost-savings," Srebnik told BNA Feb. 25.

Legal Underpinnings of PADs.

In hospitals, the legal and ethical implications of PADs largely are the concern of the physicians who make the treatment decisions, but the interest of hospitals is not insubstantial. In states without PAD statutes, their use is founded on various indirect sources of legal authority including statutes regarding the creation of durable powers of attorney and statutory and case law on involuntary treatment, according to a paper by Seattle attorney Elizabeth M. Gallagher.

The Centers for Medicare & Medicaid Services final rule on patients' rights (71 Fed. Reg. 71378, 12/8/06) incorporates into hospital conditions of participation the requirement that patients be provided the opportunity to "participate in the development and implementation of his or her plan of care." The rule's preamble said this supports "the patient's right ... to formulate advance directives and have hospital staff and practitioners ... comply with these directives."

The regulations apply equally to PADs, as CMS made clear in the interim final rule (64 Fed. Reg. 36069, 36075, 7/2/99) when it stated that CMS interpretive guidelines for state survey agencies would "further describe the aspect of advance directives that relates to psychiatric emergencies to place a greater emphasis on and encourage responsiveness to these situations."

The federal Patient Self-Determination Act of 1990 (PSDA) imposes other administrative requirements, directing covered health care facilities to ask patients if they have an advance directive, inform them of any rights under state law to prepare one, ensure that hospital staff comply with state laws requiring that such directives be respected, and educate their providers about these legal instruments. As there is no enforcement mechanism in the law, however, Gallagher described its significance as “largely precatory.”

“The greatest potential for cost-savings due to PADs likely would be to 'divert' patients from getting admitted to hospitals.”

Debra Srebnik, University of Washington, Seattle

Elements of Performance in the Joint Commission's Hospital Accreditation Standards chapter on the provision of care have their own requirements. A well-written PAD will contain much of the information that hospitals are required to collect under EP 12.40--which will be revised, expanded, and renumbered as EP 09.05.01 effective January 2009--upon admission or intake of patients at risk of harming themselves or others. Accreditation standards also require hospitals to determine whether a patient has a “behavioral health advance directive” and ensure that direct care staff are made aware of the directive.

Improving Quality, Reducing Costs.

Beyond these considerations, however, are hospital benefits relating to quality of care and the reduction of lengths of stay and their attendant costs, including court costs related to involuntary commitment proceedings.

“PADs potentially have an important role to play in helping emergency departments provide better care,” Jeffrey Swanson of the Duke University School of Medicine department of psychiatry & behavioral sciences told BNA. “Many severely mentally ill individuals during a crisis present to acute-care facilities where they are not known by clinicians; having a PAD available through an electronic registry or other means can give clinicians a precis of the patient's history and treatment--what has worked in the past and what has not,” he said.

PADs also can provide advance informed consent for treatment, thus avoiding involuntary commitments, and can alert staff to medical conditions and allergies, Swanson said. Furthermore, a recent study coauthored by Swanson, due to be published in an upcoming issue of the *Journal of Mental Health*, found that consumers who worked with trained facilitators to complete a PAD had fewer subsequent instances of coercive interventions such as forcible delivery to care.

Elbogen said it is wrong to believe that people use PADs to refuse all treatment. In a study of a representative sample of the population of clients (average age 42 years) in the public mental health system in North Carolina who had been assisted to prepare a PAD, not one participant refused all medications and or treatment, he told BNA. Ninety-four percent gave advance consent to treatment with at least one psychotropic medication, 77 percent refused some medication, 76 percent gave reasons for the refusal, and 72 percent listed specific side effects of the refused drugs.

Elbogen's study found that 88 percent of PADs gave advance consent to hospitalization and 62 percent documented advance refusals of admission to particular hospitals. Statements included "I want to go to X because it is closest to my parents and they treat me well there" and "I do not wish to go back to Y. I was thrown in a dark room and am scared and was hurt by another patient last time."

In a two-year study in Washington of physician experiences with more than 100 patients with PADs, Srebnik found the doctors considered the majority of PADs to be reasonable and followed their instructions approximately two-thirds of the time.

Protecting Hospital Staff.

Elbogen, Srebnik, and Swanson all agreed that PADs are of great value in alerting emergency staff to potential violent behavior. Elbogen cited a 1990 study in which simply flagging the charts of patients with a history of violence in the ER resulted in a 90 percent reduction in staff and patient injuries.

PADs provide other benefits for hospitals. In the North Carolina study, 52 percent of consumers included instructions to hospital staff on ways to reduce reliance on restraints and seclusions. Statements included: "Staff needs to know if I'm hearing voices to run, then I'm not wanting to hurt myself or anyone else and I just want to be talked to"; "I want a shot if I get out of control"; and, "If staff is trying to restrain me, they should know I have a portocath." Seventy-five percent wrote of wanting to be treated with respect and listened to. One said, "Staff should know if I'm crying I can't ask ... but need someone to talk with me otherwise I'll hurt myself."

Both relapse factors and protective factors were described. "All subjects listed at least one risk factor for relapse, with 58 percent giving nonadherence with medication or other treatment as a relapse factor," Elbogen said. Twenty percent described detailed behavioral patterns of decompensation.

Swanson addressed the value of PADs containing a limited waiver of confidentiality, which can facilitate contact with outpatient clinicians who know the patient and with family members.

Marvin Swartz, head of the division of social and community psychiatry at Duke's psychiatry department, told BNA that the potential role of proxy decisionmakers is another underappreciated benefit of PADs.

"Very often clinicians are stymied in gathering information and negotiating and implementing treatment when working with very ill mentally ill patients," he said. "Many clinicians would welcome the opportunity to bring in a trusted family member to provide key information, aid in discussions with the patient and in making decisions when needed."

Despite PADs' many documented advantages, however, few of those interviewed for this article were optimistic that PADs will soon see widespread use. "It has taken over 20 years for health care advance directives such as durable powers of attorney and living wills to be accepted and simplified into something like the POLST [physician's order for life sustaining treatment]," Srebnik said, "so it will likely take some years for the value of PADs to be

acknowledged, particularly given the stigma that people with mental illnesses face in getting their views heard. It will take a process of transforming clinician/doctor attitudes and behavior over time.”

One thing that does not stand in the way is consumer acceptance, research shows. There is a “large latent demand” for these instruments, Swanson said. Although PADs were found to have been completed by only 4 percent to 13 percent of mental health consumers in five cities surveyed in a study published in February 2007, two-thirds to three-quarters of consumers said they would like to complete a PAD if given the opportunity and necessary assistance. Each expert interviewed by BNA said that facilitated completion of a PAD often is the first time a patient has been asked about their preferences, a process that patients say is empowering even if the document is never used.

Impediments to Use.

What stands in the way of broader use of PADs is other legal and practical limitations.

According to Gallagher, a major problem is that the “groundswell of interest [in PADs] largely precedes the development of a coherent body of governing law ... serious questions remain concerning the scope of their enforceability, particularly in the context of involuntary treatment.”

PADs are “qualified and nested in larger structures of law and policy that protect the interests of parties other than the patient,” Swanson explained. If a conflict arises, these tend to favor the clinician's professional judgment over the patient's manifest wish to avoid standard treatment.

Physician attitudes and education are another issue, as indicated by the fact that even the American Psychiatric Association, which might be expected to advocate for their use, has no formal position on PADs, a spokesperson told BNA. The hurried atmosphere and stresses of the ER are another factor. Researchers found that even when a well-written and informative PAD is available in the patient's record or electronically from a state or other registry, physicians usually do not look at them, Swanson said. The promise of PADs will not be realized until better ways are found to get them in a timely manner to frontline clinicians who are managing psychiatric emergencies and to have clinicians follow them, he told BNA.

By Susan Carhart

*Most of the research papers discussed above may be found on the Web site of the National Resource Center on Psychiatric Advance Directives, <http://www.nrc-pad.org/index.php>, under the heading “Current Research.” Elizabeth Gallagher's paper appeared in Vol. 4 of the American Psychological Association journal *Psychology, Public Policy and Law*.*

Copyright 2008, The Bureau of National Affairs, Inc.