

# Psychiatric Advanced Directives Face Obstacles

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BY JEFF EVANS  
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ATLANTA — The potential benefits of advanced directives and other plans for future treatment during psychiatric incompetency have not received the attention they deserve from the mental health community, speakers said at the American Psychiatric Association's Institute on Psychiatric Services.

Plans for future treatment that take the form of psychiatric advanced directives, crisis cards, and joint crisis plans are well accepted in many circumstances by psychiatric patients at risk for future hospitalization. But the infrastructure to uphold the legitimacy and continuity of such plans often does not exist or is circumvented by conflicting laws.

Psychiatric advanced directives (PADs) are "very often not something that the person thinks up themselves. It's often something that we as advocates invite a person to consider," said Peter Stastny, M.D., of the department of psychiatry at Albert Einstein College of Medicine, New York.

A PAD can be a written instruction, a health care proxy, or both, and sometimes a living will. New York state requires that one person be the proxy for a patient's physical and mental health care.

Crisis cards allow patients to document their own wishes independent of a clinical team. On the other hand, patients collaborate with their personal contacts and treatment teams to create joint crisis plans to provide for care when the patients are not well. Patients who are offered a PAD typically have some psychotic symptoms in addition to a schizophrenia spectrum disorder or mood disorder.

## Patients Generally Support PADs

In face-to-face interviews with 1,100 patients in five states, 73% said that they would want to complete a PAD. Yet only 7% of patients had already done so, reported Jeff Swanson, Ph.D., of the department of psychiatry and behavioral science at Duke University, Durham, N.C.

Patients were more likely to want an advanced directive if they were female, were of a racial or ethnic minority, had a history of self-harm, were under heavy external pressure to take medications, had police involved in a prior crisis, and had a low level of personal autonomy or mastery.

Patients who had none of these six characteristics had only a 55% probability of wanting a PAD. But patients who had all six had a 98% probability of desiring a PAD, Dr. Swanson said.

In interviews with 20 psychiatric patients who received training in how to create a PAD in New York, Dr. Stastny and his associates discovered that the patients understood the meaning of advanced directives and the important responsibility they give to patients.

The PAD was often seen as helpful rather than as antagonistic, Dr. Stastny said.

Half of the patients chose to create a

PAD; the other half did not. The patients had been in the care of state-run or non-profit mental health clinics for 10-20 years and had been hospitalized many times.

Patients with a PAD could select psychiatric medications they preferred to receive and those medications that they specifically did not wish to receive. They had to make a special effort to indicate that they preferred to receive no psychiatric medications since this was not one of the options stated on the PAD form.

They also could indicate which treatment facilities and doctors they preferred. Another section allowed patients to list approaches that helped them when they were having a hard time. "Everyone seemed to be concerned with improving their treatment and their chances of getting the best possible treatment," Dr. Stastny said.

The training included how to select a health care proxy and determine what authority that person might have.

The patients completed the training by selecting a proxy. Many of the patients selected a sibling, an uncle, or a more distant family member, since they did not want to burden their parents further. Some patients wanted their primary health care provider to be their proxy, but this might present a conflict of interest.

The 20 patients in Dr. Stastny's study were among 6,000 patients in New York who were trained in writing PADs for 1.5 years as part of Kendra's Law, which was enacted in 1999. Kendra's Law provided about \$1 million in funding for written PAD training. Kendra's Law permits court-ordered, assisted outpatient treatment in New York to individuals with mental illness who may deteriorate in the future because of a history of lack of compliance with treatment for their illness. Their lack of compliance may have caused them to be hospitalized, receive treatment services in a correctional facility, or act violently toward themselves or others.

The booklet that New York patients received as a part of PAD training was taken out of circulation because the New York State Office of Mental Health considered the PAD forms to be too complex for patients, Dr. Stastny said. The state no longer funds the PAD training project.

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## Lack of Support Stymies PADs

The reform of advanced directives in psychiatry is not a progressive movement that is gathering support and growing in prac-

tice, said Kim Hopper, Ph.D., an anthropologist at the Nathan S. Kline Institute for Psychiatric Research in Orangeburg, N.Y.

Reform is a defensive maneuver against a set of coercive measures in the community, he said.

Some states have loopholes that allow civil commitment statutes to trump PADs in practice. In some cases, the PAD may be circumvented if the directions it contains go against community standards of care.

If patients don't expect the system to respond, Dr. Hopper asked, then why should they go through the work of actually creating the PAD when they may be setting themselves up for bitter disappointment? "That's the highest risk of this kind of intervention," he said.

PADs, crisis cards, and joint crisis plans will face obstacles in becoming legitimate means of directing future treatment unless they are given official endorsement, are authorized and archived by respected sources, and can be easily accessed at treat-

## Plans in England Face Trouble, Too

In England, plans for future treatment also have largely been developed as a reaction to an increasing demand for fewer restrictions on involuntary hospitalization or outpatient commitment for noncompliant patients who may be dangerous to themselves or others.

Highly publicized cases of violent crimes committed by mentally ill individuals in England have brought about several draft bills for mental health reform that take away some of the rights of patients to direct their future treatment when they are unable to do so on their own behalf.

Currently, a draft bill on mental health reform includes a very broad definition of a mental disorder that involves "virtually any disturbance of psychological functioning" and a broad definition of minimal treatment that includes rehabilitation and habilitation (training, social skills, and education). The bill says that if patients pose a substantial risk of harm to others, the patients must be hospitalized against their will, even if there is an alternative, lawful treatment, noted George Szmukler, M.D., dean of the Institute of Psychiatry at King's College, London.

PADs currently cannot be used in England. Dr. Szmukler and his colleagues introduced two alternatives to a PAD—crisis cards and joint crisis plans—in a pilot study conducted in a community psychiatric service of 106 patients with psychosis who were at high risk of crisis. Many of the patients were reluctant to participate, but after 9 months 40% had agreed. All of these patients opted for a joint crisis plan.

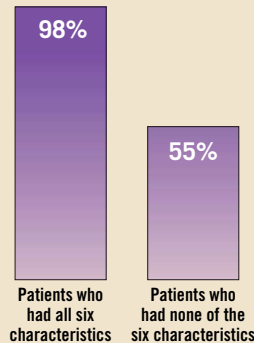
The patients who chose to participate were more likely to have an affective disorder, a history of suicidal ideation, fewer hospital admissions, and nonblack ethnicity. Although the patients had guidance, the choice of information included in the plan was up to the patients themselves. The joint crisis plans provided important information to health care providers when the patient was too ill to do so and reduced hospital admissions by 30% in the follow-up year. The plans were used in 73% of patient crises and 81% of hospital admissions (Acta Psychiatr. Scand. 1999;100:56-61).

After the pilot study, Dr. Szmukler, Claire Henderson, M.B., also of the Institute of Psychiatry, and their associates conducted the first randomized, controlled trial to assess the impact of joint crisis plans. But only 36% of the eligible patients in the study were ultimately randomized in the single-blind trial (BMJ 2004;329:136-40). Of 160 patients who had a psychotic illness or nonpsychotic bipolar disorder, significantly fewer of those who completed a joint crisis plan required compulsory hospital admission (13%) than did patients who received a control intervention (27%).

As a result, the patients with a joint crisis plan spent significantly fewer days on average as inpatients in compulsory detention than did control patients (14 days vs. 31 days). The control intervention consisted of leaflets containing information about local services, mental illness and treatments, England's Mental Health Act of 1983, and local provider organizations. ■

## Probability of Wanting a PAD

Patients more likely to want an advanced directive were female, were of a racial or ethnic minority, had a history of self-harm, were under pressure to take medications, had police involved in a prior crisis, and had a low level of personal autonomy.



ment centers. PADs, crisis cards, or joint crisis plans carried by a patient will not be taken seriously by emergency departments if the staff have no interest in these programs or if bureaucratic support is lacking, Dr. Hopper said.

An ongoing randomized study in North Carolina has shown that 79% of 123 patients who received help from a trained facilitator were able to complete a PAD within 1 month. In contrast, only 6% of 60 patients who received a referral, information on PADs, and PAD forms—but no facilitator—completed a PAD within 6 months, Dr. Swanson said.

The provision of a facilitator would, in itself, represent an investment by a mental health system to provide the service of creating plans for future treatment, Dr. Hopper noted.

The PADs were placed on the U.S. Living Will Registry (located at [www.uslivingwillregistry.com](http://www.uslivingwillregistry.com)) so that they could be accessed electronically whenever they were needed. Patients also received "dog tags" that included relevant information about their PADs, Dr. Swanson said.

Overall, 15% of the 123 patients were refused to have a facilitated PAD session, while another 4% met with their facilitator and then refused to create a PAD. All of the patients had some psychotic symptoms.