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## *CASE REPORT*

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### Psychiatric Advance Directives: Practical, Legal, and Ethical Issues

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**ABSTRACT.** Psychiatric Advance Directives are relatively new legal tools that allow competent persons to consent or refuse mental health treatment and designate a proxy decision maker in advance of a mental health crisis, during which they may lose capacity to make healthcare decisions. Psychiatric Advance Directives hold the promise of improving care during mental health crises but also raise a number of clinical, legal, and ethical is-

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sues. This article provides an illustration and critical analysis of issues raised by Psychiatric Advance Directives. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2004 by The Haworth Press, Inc. All rights reserved.]

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### **INTRODUCTION**

Psychiatric Advance Directives (PADs) are relatively new legal instruments that permit competent persons to state their preferences regarding future mental health treatment in the event of a loss of capacity to make healthcare decisions (Appelbaum, 1991; Backlar, 1995; Srebnik & La Fond, 1999; Swanson, Swartz, & Hannon et al., 2003; Winick, 1996). Some generic form of advance directives for healthcare is permitted in every state. Most commonly, these advance directives authorize a surrogate decision-maker to act in accordance with an incapacitated patient's expressed preferences about healthcare decisions, generally at the end of life. Only recently have advance directives been applied to mental health treatment in the case of incapacitated psychiatric patients.

Generic advance directive statutes vary in their treatment of mental health decision-making; some do not permit proxy decision makers to authorize certain types of mental health interventions such as psychiatric hospitalization. In addition, generic advance directive statutes generally allow medical patients to revoke their advance directives even while incapacitated, if able to communicate a choice to do so. In contrast, some psychiatric patients might wish to preauthorize treatment using an advance directive specifically designed to be irrevocable during a crisis.

Given the potential limitations of generic advance directive statutes for mental health crises, 19 states have adopted specific PAD statutes tailored for psychiatric patients who may experience fluctuating capacity to make treatment decisions. These PAD statutes allow competent individuals to document their consent or refusal of particular types of mental health treatment in advance of an incapacitating crisis. These preference documents are referred to as "instructional directives." Some PAD statutes also incorporate the ability to appoint a proxy deci-

sion-maker authorized to make mental health treatment decisions, while some statutes allow designation of a proxy decision-maker through separate statutory provisions for health care power of attorney. These new PAD statutes generally limit revocation of a PAD to periods of competency to make health care decisions and remain legally binding during periods of decisional incapacity (Fleischener, 1998).

Despite increasing interest in and the promulgation of new statutes authorizing PADs, very little research or case analysis has been conducted with these new legal instruments. Little is known about the demand for PADs, how persons with mental illness might seek to use them, nor the response of providers or the courts to potential conflict arising from PADs (Swanson et al., 2003).

Enthusiasm for PADs has grown because they are seen as vehicles to promote patient choice and empowerment (Hoge, 1994; Kapp, 1994) and as a potential mechanism to avoid involuntary and/or coercive treatment (Amering, Denk, & Griengl et al., 1999; Backlar & McFarland, 1996; Brock, 1998; Srebnik & La Fond, 1999; Sativs, 1999; Svulescu & Dickenson, 1998). There are a number of potential substantive and procedural barriers to use of PADs (Srebnik & Brodoff, 2003; Swanson et al., 2003). PADs may be difficult to complete for persons with severe mental illness. While resources are available in some states to aid in completion of PADs, the legal forms required to execute a valid PAD may be somewhat daunting to a mentally ill individual. Generally, PADs must conform to a specific format including identification of witnesses and notarization. The PAD then must be filed in the medical record wherever it might relevantly come into use. Thus, without some tangible assistance in completing these legal forms, mentally ill individuals may not readily complete the process on their own. Whatever instructions or preferences are stated in the PAD must be clear and specific enough to guide future clinical decision-making.

It is well known that medical advance directives are often too vague to provide meaningful guidance to clinicians or suffer other barriers that make them ineffective (Howe, 2000; Teno, Lynn, & Wenger et al., 1997; Wolf, 1991). Psychiatric advance directives may encounter similar problems, compounded by the potential cognitive impairment of mentally ill persons preparing a PAD. Stand-alone instructional directives without the appointment of a healthcare power of attorney may be difficult to implement. Thus, instructions that cannot be reinterpreted and clarified in real time by a proxy may be particularly frustrating. Moreover, some persons with severe mental illness may be so isolated

and/or mistrustful that they are not able to identify a healthcare agent to serve this function.

Another frustrating barrier to use of PADs may be their potential lack of availability in crises. Persons in crisis may find themselves in a number of different emergency settings, each with distinct medical record systems. Thus, unless the patient had the foresight to make his/her PAD available in each emergency setting, the PAD will likely be unavailable. In addition, the individual in crisis may not be coherent enough to indicate that he/she has a PAD and clinicians may not be attuned enough to these new legal instruments to inquire.

The Patient's Self-Determination Act (PSDA) of 1991 introduced a new set of federal requirements intended to implement advance directive policies at all healthcare facilities that receive federal funding through Medicare and Medicaid programs (Greco, Schulman, & Lavizzo-Mourey et al., 1991). Mental health-legal scholars and other advocates believe PSDA requirements apply equally to psychiatric facilities and general hospitals. The PSDA requires that healthcare facilities: (1) inform patients of their rights under state law to make decisions concerning their own healthcare, including the right to accept or refuse treatment and the right to formulate advance directives; (2) to document in the patient's current medical record whether or not the patient has an advance directive; (3) formulate policies for implementing patients' rights, including the right to prepare advance directives, and inform patients in writing of the specific implementation policies; (4) insure compliance with state law respecting state directives; and (5) prepare education for staff and the community on issues concerning advance directives (U.S. Code, 2000). Thus, in states with specific PAD statutes, the PSDA requires that healthcare facilities implement PAD policies to the same extent that they are required to implement medical advance directives.

Other concerns about PADs include the lack of requirement or mechanism to determine a person's competency to prepare a PAD. In North Carolina, witnesses to the execution of a PAD must attest that the person drafting the PAD is of "sound mind," but there is no requirement for clinical determination of capacity or competency to prepare the PAD. In addition, because the PAD may also include advance consent to hospital admission, administration of medication or even a procedure such as electroconvulsive therapy, the PAD presumes that the individual is competent to give advance consent and appreciates the risks and benefits of his/her treatment preferences. This may be a particular problem if

a PAD is not updated periodically to reflect changes in the patients' preferences or new knowledge about mental health treatment.

A frequent concern about PADs raised by clinicians is the potential conflict between community standards of care and preferences stated in a PAD. For example, a patient may request an outmoded or inappropriate treatment or one at variance with community practice standards. Further, a patient may request a treatment plan that is not feasible such as requiring transport to a facility at some distance or a treatment course that is otherwise impractical. Many PAD statutes acknowledge these potential problems and provide provisions to preempt treatment that deviates from community practice standards or is otherwise unfeasible.

Clinicians also have expressed discomfort with the provisions in PADs that allow the individual to relinquish the right to change his/her mind during a crisis—a so-called Ulysses contract, referring to Ulysses' wish to be bound to the mast to aid him in resisting the call of the sirens (Cuca, 1993; Dresser, 1984). In the ancient Greek myth, Ulysses instructs his men not to release him from the mast even under protest. Clinicians may well be confronted with protesting patients refusing a treatment previously authorized in a PAD. Clinicians under such circumstances find themselves in the ethical quandary of selectively recognizing the previous written wishes of the patient and ignoring his/her current expressed wishes. Thus, the clinician must make a difficult decision about where the "true" decision-making authority of the person resides—with the document prepared in advance while the person was competent, or with the presently-stated wishes of the person who is experiencing a psychiatric crisis.

The following case vignette drawn from a composite of clinical cases illustrates many of the important clinical, ethical, and legal issues raised by PADs.

### ***Case Report***

John is a 28-year-old single white male with an 8-year history of schizophrenia and one prior hospitalization. He was petitioned for involuntary commitment by his parents due to an exacerbation of his psychosis. John had executed a PAD one-year prior to admission during an evangelical religious retreat where he had discussed his feelings of humiliation about his psychiatric hospitalization. At the time of the admission, his parents were unsure whether the PAD could be used to authorize admission so proceeded to commitment with the hope of revisiting the PAD once John was hospitalized.

Prior to admission, John was functioning well in the community, holding a job with a technology company as a computer specialist. He discontinued his anti-psychotic medication, olanzapine, several weeks prior to admission due in part to excessive weight gain. After discontinuing his medication, he became increasingly isolated, withdrawn, and paranoid. He also became hyper-religious, praying on his knees nearly constantly. In the past several days, he developed a grandiose delusion that he was a messenger of God with prophetic powers. He also acknowledged hearing two voices giving a running commentary on his religious conduct. One voice directed him to “scarify himself” and he cut his wrists and arms. For unclear reasons, he began refusing all but liquids and refusing any medications.

During college, John joined an evangelical religious group and gradually became preoccupied with a “call to Christ.” While later proselytizing on campus, he stopped attending classes and was eventually barred from campus when his public preaching became disruptive. Approximately a month later, he was involuntarily hospitalized. He found the hospitalization dehumanizing and unwaveringly believed that the hospitalization was a form of religious persecution. He has no history of violent or dangerous behavior or prior suicide attempts or self-injury. He has no history of substance abuse and he has had previous trials of two of the older anti-psychotic medications. He developed side effects related to these older medications, including early signs of tardive dyskinesia, a potentially irreversible movement disorder. While taking olanzapine, he developed a 50-pound weight gain over the course of 4-6 months.

Of note, John has never had a complete resolution of his hyper-religiosity. Even while taking medication, he believes that he has a special mission from Christ but the intensity of his proselytizing diminishes. While he disputes his psychotic diagnosis, he believes that olanzapine helps him sleep and calms his nerves.

John’s parents are both college educated and his father is a professor of economics at a local university. There is no history of mental illness in the family. John’s medical records contain an apparently legally executed PAD, which includes an instructional directive as well as healthcare power of attorney. In his instructional directive, he refuses hospitalization unless admitted to a “Christian hospital.” He refuses forcibly administered medications and consents to treatment with haloperidol or another “time-honored” medication. He has designated his mother as healthcare agent if determined to be incapable.

Having been admitted to the hospital under involuntary commitment, the treating psychiatrist determines that John meets the statutory definition of incapacity in that he “lacks sufficient understanding or capacity to make and communicate mental health treatment decisions.” The treatment team wishes to meet with John’s mother to review the PAD and seek guidance from her about subsequent treatment decisions.

The treatment team raises a number of issues to consider in reference to John’s PAD: (1) Did John create the PAD while capable? (2) Is a patient with schizophrenia, who never achieved full remission, capable of executing a valid PAD? (3) Was John’s PAD, including specific decisions about medications, informed by present knowledge of risks and benefits of these decisions? (4) Was John adequately educated about the pros and cons of the treatment he proposed in the PAD and whether it was feasible? (5) Was John’s mother adequately involved in the preparation of the PAD so that she is prepared to act as a proxy decision maker?

### ***DISCUSSION***

In retrospect, John’s competency to execute a PAD could be questioned, although there is no statutory requirement or mechanism to determine competency during the execution of a PAD beyond the attestation of witnesses that the individual appears to be of “sound mind.” As a result, a PAD has to be taken at face value and presumed to be valid. PADs also presume a clear demarcation between an incapacitated state and full recovery. During recovery, with the restoration of capacity, it is hoped that the mentally ill person will regain an awareness of or insight into the ill state and be able to formulate a set of plans and preferences that might be helpful during a future illness. John’s case illustrates the imprecise boundaries between “illness” and “health” and the potential problems of executing a PAD in a partially remitted state. Knowing that John likely never regained full insight into his illness when he executed the PAD undermines the confidence clinicians can place in the PAD instructions. John’s unclear mental state during the time he drafted the PAD also calls into question the extent to which he was fully able to appraise the risks and benefits of preferences expressed in his PAD. In many states, the standard for decision-making by the healthcare agent is to make decisions consistent with the expressed preferences and wishes of the mentally ill person. The proxy decision maker is often barred from making judgments that give preference to

the “best medical interests” of the patient if they conflict with expressed or implied preferences. In John’s case, his mother is put in a difficult position because she likely views many elements of the PAD, such as the desire to be admitted to a “Christian hospital,” as a product of his illness.

Because John’s PAD was already trumped by involuntary commitment proceedings, the treatment team might be tempted to disregard the PAD in its entirety. However, PAD statutes generally instruct providers to honor remaining sections of the PAD even if some sections do not conform to community practice standards or are infeasible. Thus, while the team has over-ridden the preference to only be admitted voluntarily to a “Christian hospital,” the team is still obligated to consult with John’s mother and act consistently with remaining elements of the PAD.

Unfortunately, John’s stated preferences about medication are likely dated. While he requests haloperidol or another “time-honored” medication, he subsequently developed tardive dyskinesia and was switched to olanzapine, a second generation anti-psychotic with lower risk of tardive dyskinesia relative to haloperidol or other first generation antipsychotics. John’s mother might presume that his most recent preference would be for olanzapine but on this medication, he developed significant weight gain and she is faced with selecting yet another medication, which she believes will be consistent with his preferences. Unfortunately, John’s failure to revise his PAD over time leaves his mother and the treatment team with inadequate guidance.

While this case illustrates many of the potential challenges posed by PADs, scholars recognize the need for more definitive research on these new legal instruments (Amering et al., 1999; Backlar, McFarland, & Swanson et al., 2001). Will PADs be used prescriptively, to specify care, or proscriptively, to bar unwanted treatment, or both? To what degree do PADs conform with clinical judgments of appropriate treatment, and what happens when they do not? How will PADs be implemented in systems of care in the “real world” and how will clinicians respond to potential ethical challenges and perceived legal liabilities posed by PADs? What is the demand for PADs among consumers, and what forces motivate the desire for PADs? Is formal assistance necessary to facilitate effective PADs? If offered assistance, will a substantial portion of persons with SMI complete PADs? Might PADs with certain features enhance treatment engagement, improve the process of care surrounding psychiatric crises, and provide a greater sense of autonomy for persons with severe mental illness? Might PADs have nega-

tive consequences for some, e.g., if PADs raise unrealistic expectations, or if they are co-opted by family members and clinicians as ways to leverage greater adherence with prescribed treatment?

The answers to many of these questions await further research. A large-scale longitudinal study funded by the National Institute of Mental Health is currently underway at Duke University Medical Center, and is designed to provide needed information about the challenges, benefits, and limitations of PADs. The randomized study will enroll more than 500 patients with serious psychiatric disorders. One-half of the subjects will be presented with the opportunity to create psychiatric advance directives and/or authorize health care proxies with the help of a trained facilitator. The other group will also have the opportunity to create PADs, but will be given the resources to do so on their own. The second group of patients will serve as a comparison group. PADs will be filed electronically with the U.S. Living Will Registry, a computerized service that stores medical advance care documents and makes them available at any time to authorized healthcare facilities. Subjects and their clinicians will be followed up with structured interviews at 1 month, 6 months, and 12 months to examine the rate of completion of PADs, the structure and content of these documents, and subsequent treatment engagement and crisis management outcomes. The study underway will provide information about one state's experience with facilitation and outcomes of PADs, so that policy-makers may be guided in implementing PADs elsewhere.

Psychiatric advance directive hold clear promise for improving patient-centered mental health care. As they come into greater use, states gain experience with their implementation, face legal challenges, and are studied in real world settings, far more will be understood about their true pitfalls and promise.

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