

# **Psychiatric Advance Directives and Board Certified Psychiatric Pharmacists: An Opportunity for Patient Empowerment**

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## **Introduction**

In times of psychiatric crisis, the most vulnerable population, those with severe, often debilitating, mental illnesses, may be least able to advocate for their care and make their treatment preferences known. The psychiatric advance directive (PAD) is a transportable vehicle used to empower persons with a psychiatric disability to advocate for their treatment desires even when incapacitated during an acute exacerbation.

Psychiatric Advance Directives, also called Mental Health Advance Directives in states that recognize them (Figure 1), are legal tools developed prior to a psychiatric crisis, to allow individuals to clearly identify preferences for future mental health treatment. At the time when this document is developed, the individual is competent, autonomous, and able to articulate their wishes.<sup>1</sup> The PAD generally contains patient treatment preferences, medical and treatment histories, comorbid conditions of importance for the treating physician or facility, emergency contact information, and history of medication treatment and side effects that may help the treating clinician make informed treatment decisions for the current admission.<sup>2</sup> The document may also include identification of a designated healthcare agent charged with communicating the wishes of the person in crisis.<sup>3</sup> Further information about PADs can be found at the National Resource Center on Psychiatric Advance Directives at [www.nrc-pad.org](http://www.nrc-pad.org). Once the PAD is created it can be stored electronically at an internet site. The Living Will Registry is a repository that contains all types of advance directives, including PADs which can be stored for a onetime fee of \$125.00. Use of this registry also includes provisions for protection of healthcare information. Information about this registry is available on the internet at [www.uslivingwillregistry.com](http://www.uslivingwillregistry.com). On an annual basis, a person storing advance directives at this website is notified that the document should be reviewed and updated as desired.

Not all states recognize PADs and each state may have individual rules about how to file the documents. In those states with advance directive provisions, limited knowledge about the document and difficulties explaining its use in the inpatient setting were identified as barriers to effective use of the PAD.<sup>1</sup> Furthermore, in these states clinicians educated about PADs and associated legal implications viewed the use of an advance directive more favorably than counterparts who did not have the education.<sup>3</sup> Other barriers to PAD use could include lack of resources (e.g. unable to access form, inability to use a computer, lack of funds for lifetime filing fee for the Living Will Registry), failing to file the PAD in a central location or communicate its existence or incorrectly executing the document. In addition, the definition of 'incapacity' varies by state and may contribute to confusion about when and if the PAD instructions should be implemented during an acute exacerbation. Concern about whether or not PAD directions can be overridden, in what circumstances, and the legal liability of such action by the clinician also prevents effective use of the PAD.<sup>4</sup>

This article will review select literature surrounding the utility of PADs, clinician perspectives related to the use of one, including clinician attitudes on their use, and the results of facilitation in completing a PAD. Board certified psychiatric pharmacists (BCPP) practice in a variety of healthcare environments and actively participate in patient care. BCPPs often develop a unique partnership with the person suffering from a mental illness to enhance the person's ability to advocate for the best care for the individual. These qualifications and background of the BCPP may provide an opportunity to facilitate development and completion of a PAD prior to need.

## **History**

The use of a PAD is not a new concept. They have been in existence since the 1980's. Originally developed as a vehicle for the chronically mentally ill to communicate information related to their mental health treatment decisions during periods of exacerbation and inability to self-advocate, this use continues to this day.<sup>5-8</sup> The PAD has two components: identifying mental health advance instructions and designating a proxy for health decisions, that can be used independently or in combination to identify specific treatments.<sup>5-8</sup>

Twenty-five states have PAD statutes.<sup>9</sup> (Figure 1) The stated goal of the PAD is to serve as a vehicle for self-determination when the person is not competent due to a mental illness acute exacerbation that would impair the person's ability to function and advocate for appropriate care. Some of the newer statutes contain contradictory wording that allow clinicians to supersede treatment preferences they consider inappropriate. The rationale for these treatment decisions made by the patient and how these decisions are communicated to families and healthcare agents may serve to either strengthen PADs and broaden their application or limit their use.<sup>9</sup>

Swanson and colleagues compared the various aspects of the medical advance directive (MAD) and the PAD. As originally conceptualized, the MAD intent was to provide a legal vehicle for competent persons to express their wishes for medical treatments when they were unable to advocate for themselves although the extent to which this has been operationalized varies by state. Often times MADs contain 'Do Not Resuscitate' orders. These documents, first brought forth in 1976, contain either written instructions regarding medical treatments and conditions (generally referred to as "living wills") or the appointment of a decision maker (through a durable power of attorney) or both components.

Later the federal Patient Self-Determination Act of 1990 sought to enhance the use of MADs by requiring healthcare institutions receiving federal reimbursement to make this information available and inform patients of their rights to prepare MADs. Personnel at healthcare facilities must ask if the patient has an advance directive and document this action was completed. If one is in effect, the treating facility is required to place a copy of the directive (or power of attorney) in the individual's treatment record.<sup>9</sup> In addition, healthcare facilities must educate providers about the advance directives and encourage the provider to respect the patient's wishes as expressed in the directive.<sup>9</sup> Interestingly, when a person arrives at a hospital for admission it is required that the organization inform the person about advance directive options but most discuss only MADs not PADs.

### **Identification of at Risk Populations Who Might Benefit: Clinician Perspectives**

Grappling with cognitive dysfunction in persons who have experienced a psychiatric crisis may present challenges for the patient, family members/support system and the treating clinicians. Differences in the circumstances surrounding utilization of MADs versus PADs can significantly impact healthcare providers and influence their willingness to work with the individual as delineated in the directive. Persons with MADs may be facing end of life issues or are no longer able to make treatment decisions as a result of accidents or disease progression. Persons with PADs may experience more than one psychiatric crisis and present with cognitive impairment or changes as consequences of chronic mental disorders. Problems inherent in persons with long-term psychopathology are the potential for changes in the person's baseline ability to render personal healthcare decisions. The diagnostic criteria for schizophrenia recognize impaired thought processing, altered realities, and cognitive impairment.<sup>10</sup> The extent to which these effects alter the personality of the affected individual has not been

determined.<sup>10</sup> Criteria for mood disorder also recognize impairments in decision-making. Insight may be reduced or completely lacking with both conditions during the acute phase of the mental illness. These limitations underscore the need for a PAD.

### **Review of Select Current Literature: Clinician and Patient Pros and Cons**

Both quantitative and qualitative assessment of PAD use has been reported in the literature. Swanson and colleagues evaluated various stakeholders' opinions and their perceived value of the PAD in the care of patients with schizophrenia.<sup>11</sup> Three groups were surveyed – persons with a severe mental illness (SMI), such as schizophrenia (n=104), family members of persons with a severe mental illness (n=83), and clinicians who treated patients with SMI (n=85). Overall, PADs were underutilized (Table 1). Of note, the SMI group indicated a desire to complete a PAD if assistance was provided. In addition, clinicians reported few of their patients had a correctly executed PAD but would encourage their patients to complete a PAD. Within the SMI group, persons who were interested in completing a PAD identified barriers to complete the document as a lack of understanding about a PAD, that completion of the document would take much time and trouble, a belief that the PAD would not make any difference in treatment during an acute exacerbation, and various other reasons. Significantly more SMI persons and family members than clinicians felt that the PAD would help persons with a SMI stay well. Significantly more family members than SMI persons or clinicians felt that the SMI person should choose a person who they trusted to make treatment decisions in the future if the SMI person became acutely ill. Significantly more SMI persons than family members or clinicians felt that the ability to change their mind during the acute phase of the illness was important even if advance written instructions were prepared. Significantly more SMI persons and family members, when compared with the clinicians, felt that a legal penalty should be enacted if the PAD instructions were not

followed during crisis treatment and that failing to create a PAD would put the SMI person at greater risk of receiving undesired medications during a crisis treatment. Significantly more SMI persons than family members or clinicians felt that they might go without any needed treatment if a PAD was not created.<sup>11</sup>

Srebnik and Russo evaluated how well PAD instructions were followed during crisis events. Electronic records were reviewed to identify the study population (n=475) who were older than 18 years and who had had at least two psychiatric emergency services or hospitalizations in the previous 2 years. Thirty-six percent were ineligible to participate for a variety of reasons including incarcerations, inability to sign an informed consent, or lack of English language fluency. One hundred six consumers who received outpatient mental health care and who completed a PAD were enrolled in the study. The study population included 58% women, with an average age of 41.9 years with 24% ethnic and minority groups. A primary diagnosis of axis I schizophrenia spectrum disorder occurred in 48% of the study population. Thirty-seven percent of the study population had an axis II personality disorder diagnosis and 5% had a developmental disability. Directives were placed in the participant's medical record and sent to a centralized 24-hour crisis service. The participants were provided a wallet card and necklace or identification bracelet providing information about the existence of the PAD and where it could be accessed. In addition, the electronic community mental health record was flagged to identify the fact that the participant had a PAD. Emergency room providers as well as hospital health care professionals had access to this electronic record. Several items were measured to determine how well PAD instructions were followed. Both the participant and the outpatient case manager were interviewed on a quarterly basis with a Directive Use Interview to determine whether the PAD had been used or if a hospitalization or crisis service after hours contact had triggered use of the PAD. A chart review of crisis service and hospital and electronic patient information

during the study period was conducted. The investigators completed utility ratings of the directive content that included 19 different topics covering two broad categories—treatment instructions and non-treatment personal care instructions. The treatment instructions topics included: electroconvulsive therapy, medications agreed to take, medications refused to take, pre-emergency instructions, hospital alternatives, hospitals to avoid, instructions about medications not listed in the directive, preferred hospitals, hospital versus alternatives, and emergency service: seclusion and restraints. PADs were accessed in only 20% of the 90 crisis events that occurred in 35 patients. However, when the PAD was accessed during the crisis situation, 67% of directive instructions were consistent with crisis care provided.<sup>12</sup> Interestingly, this is the rate range found for MADs use. While all treatment and non-treatment parameters were assessed, only results pertinent to medication therapy management are presented here. During a crisis situation, 6% of PAD instruction pertained to the use of electroconvulsive therapy and 100% of PAD instruction was followed. Relevant PAD instruction about medications the person agreed to take during crisis occurred in 74% of the situations and was followed by the healthcare team 90% of the time. In 69% of pertinent situations, PAD instructions identified medications that the person refused to take during a crisis situation, and the healthcare team adhered to this direction 89% of the time when making medication treatment decisions. PAD instruction during crisis about medications not listed in the directive were relevant in 26% of the situations and were followed 65% of the time.<sup>12</sup>

Different healthcare provider (HCP) disciplines, psychiatrists<sup>13</sup>, social workers<sup>1</sup>, and psychologists<sup>2</sup>, have provided information about how they view the PAD from their clinical practice settings. The HCPs recognized benefit with the PAD to maximize recovery and minimize unwanted interventions but also identified several barriers including concern about legal ramifications if PAD instructions were not followed. Other

identified barriers include service providers with limited knowledge of PADs, difficulty communicating to HCPs, and ability to access and correctly execute PADs.

### **How a Board Certified Psychiatric Pharmacist (BCPP) Can Facilitate the Process**

Pharmacists with advance practice experience and board certification in psychiatric pharmacy may be in a unique position to facilitate drafting and execution of a PAD. (Figure 2) Findings from several studies indicated the majority of persons with mental illnesses, when provided assistance, would complete a psychiatric directive<sup>14, 15</sup> that plainly states the rationale for a particular treatment modality.<sup>2</sup> Helping format a clear rational explanation in terms appropriate for the treating practitioner, healthcare facility, and patient may help supersede physician reluctance to follow the directive. In a questionnaire completed by psychiatrists, psychologists, and social workers, the majority of each group indicated a greater preference for honoring treatment decisions based on conventional medical concerns, such as medication side effects, compared to delusional reasoning.<sup>2</sup> This can be particularly compelling in light of the numbers of persons with a psychiatric disability who may avoid treatment if a PAD is not in place.<sup>11</sup> Interestingly, Swartz and colleagues surveyed patients with schizophrenia-related disorders and found more than one-third (up to 36%) of the psychiatrically disabled population reported treatment avoidance during a crisis due to coercion fears about treatment that would result in forced, perhaps undesired, medication treatment or involuntary hospitalization.<sup>16</sup>

Psychiatric pharmacists may help those with mental health disabilities overcome obstacles to complete a PAD in a number of ways. Research shows that PADs are underutilized for three reasons: time needed for preparation of the document, barriers inherent in a fragmented mental healthcare delivery system, and lack of familiarity with the PAD.<sup>1</sup> Psychiatric pharmacists, while not legal experts, can facilitate the process by

identifying witnesses for the document and making the existence of the document known to providers. At this time, 25 states have statutes that recognize PADs. (Figure 1) The list of states with PAD statutes can also be found at <http://www.nrc-pad.org/content/view/41/25>. Statutes vary by states and the assistance of legal counsel may be needed to help evaluate what other services the BCPP can provide. However, BCPPs have the talent to assist the patient in stating treatment preferences in clear, concise language and providing examples of medication- or treatment- related effects that were useful or problematic in previous admissions or during outpatient treatment.

Other qualifications of the BCPP to help with PAD execution include familiarity with the individual patient, often times in both stable and crisis states, his/her needs, and pertinent medication issues or concerns. If the treatment goals for the SMI population are to optimize functioning and minimize hospitalizations, the BCPP can facilitate translating patient experiences into behavioral or medication-related terms, thereby enabling other health care providers meeting the patient in crisis to provide more patient-specific care and address individual needs more comprehensively. To meet these individual needs, collection of patient preferences is needed. The Health Care Preferences Questionnaire (HCPQ) may represent one tool for BCPPs to consider using as an evaluative tool to identify treatment preferences. The questionnaire is composed of five parts covering specific health care choices, beliefs and values, and end of life issues. One section of the HCPQ provides an opportunity for discussion on treatment options based on four possible treatment dilemmas depending upon the individual's functioning level. These include the use of psychotropic medication, emergency intervention with increased aggression, use of involuntary medication, and the use of electroconvulsive therapy (ECT). Imbedded in these case studies is one other treatment modality, the use of seclusion and restraints.<sup>17</sup> BCPPs need to evaluate their time and responsibility commitments to determine if resources are available to expand their role in

their practice setting to include training and administering this questionnaire. The more desirable setting to administer the HCPQ for the stable patient is in an outpatient setting to help identify treatment preferences and incorporate this information into the PAD. In the event the patient is encountered in the inpatient setting, administration of the HCPQ at discharge or on follow-up would offer another opportunity to help facilitate PAD development.

### **Conclusion**

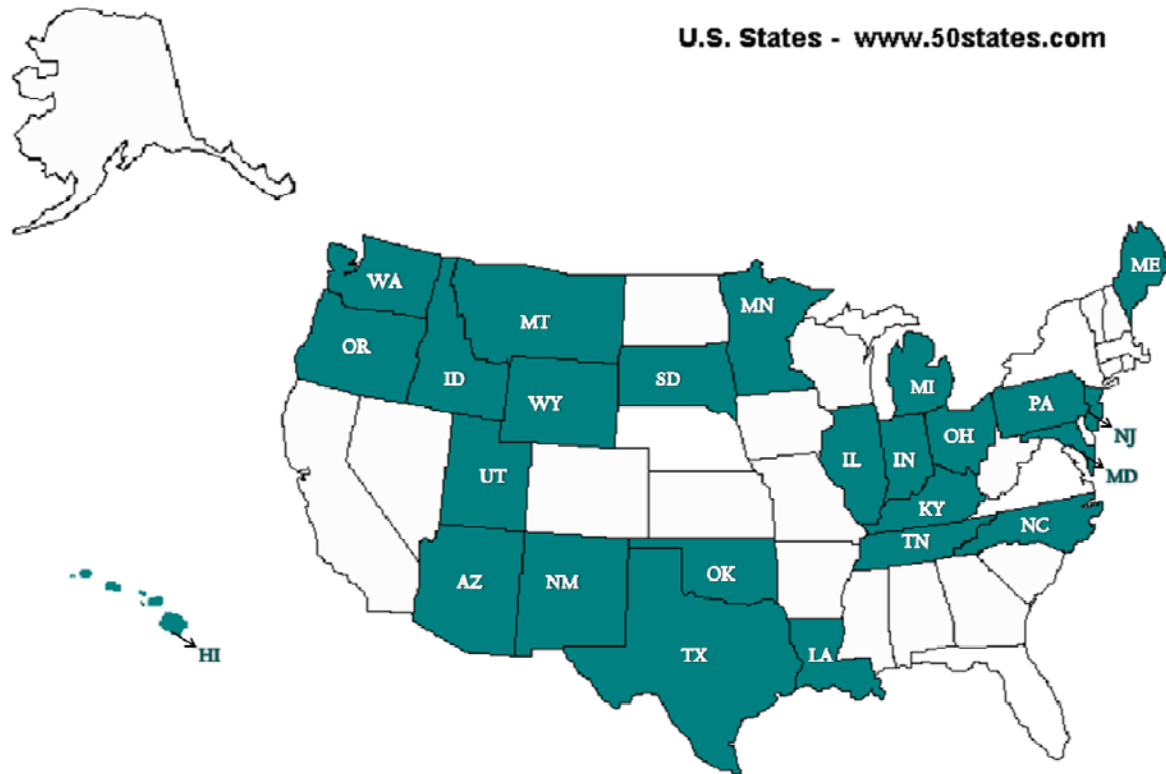
In populations at high risk for severe, often debilitating, mental illnesses, self-advocacy for psychiatric care and treatment preferences may not always be possible. The fragmented nature of mental health treatment options and knowledge of available facilities may prevent or delay appropriate care for the SMI person. The PAD, a transportable vehicle, contains pertinent information for healthcare professionals working with SMI populations. Familiarity with this document is not widespread. BCPPs can serve as facilitators for those with SMI to correctly execute a PAD and advocate for their own best treatment. BCPPs could continue to help the SMI receive continuity of care that potentially could help the person return to their highest level of functioning in the most expedient manner. Thus BCPPs are in a special position to be able to educate patients, their support systems, and health care professionals about the PAD. Specifically, BCPPs can assist patients in clearly identifying and stating medication-related desires in the PAD.

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Figure 1: States with Psychiatric Advance Directives



Colored states have statutes for a psychiatric advance directive.

**Table 1: Survey Results From Three Groups Regarding Psychiatric Advance Directives<sup>11</sup>**

Groups	SMI	FM	CL
Number of respondents	104	83	85
SMI had PAD	6.8%		12.5%
Heard of a PAD		22%	
Interested in completing a PAD	67.4%		

SMI = person with a severe mental illness

FM = family members of persons with a SMI

CL = clinicians who treat patients with SMI

Adapted from Swanson JW, Swartz MS, Hannon MA, et al. Psychiatric advance directives: a survey of persons with schizophrenia, family members, and treatment providers. *Int J Forensic Mental Health* 2003;2(1):73-86.

**Figure 2: Methods a BCPP May Utilize to Increase PAD Use**

