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## Psychiatric Advance Directives and Social Workers: An Integrative Review

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### Abstract

Psychiatric Advance Directives (PADs) are legal documents that allow individuals to express their wishes for future psychiatric care and to authorize a legally appointed proxy to make decisions on their behalf during incapacitating crises. PADs are viewed as an alternative to the coercive interventions that sometimes accompany mental health crises for persons with mental illness. Insofar as coercive interventions can abridge clients' autonomy and self-determination -- values supported by the Profession's Code of Ethics -- social workers have a vested interest in finding ways to reduce coercion and increase autonomy and self-determination in their practice. However, PADs are also viewed as having the potential to positively affect a variety of other clinical outcomes, including but not limited to treatment engagement, treatment satisfaction, and working alliance. This article reviews the clinical and legal history of PADs and empirical evidence for their implementation and effectiveness. Despite what should be an inherent interest in PADs, and the fact that laws authorizing PADs have proliferated in the past decade, there is little theoretical or empirical research in the social work literature.

### Keywords

Psychiatric advance directives; social workers; prior research; empowerment; Code of Ethics

## Overview of psychiatric advance directives for persons with severe mental illness

Individuals with severe mental illnesses (SMI) such as schizophrenia or bipolar disorder often experience episodic crises alternating with times of stability. During crises, social workers and other providers often implement mandated interventions such as involuntary hospitalization. On the one hand, many providers see these interventions as necessary to prevent harm and protect those with SMI (Swanson, McCrary, Swartz, Van Dorn, & Elbogen, 2007); on the other hand, however, many people with SMI describe these interventions as frightening, disempowering, traumatic, and a barrier to treatment (Arrigo & Williams, 1999; Swartz, Swanson, & Hannon, 2003; Van Dorn, Elbogen, Redlich, et al., 2006). Social workers thus face difficult ethical decisions when engaging in crisis

intervention. They may be required to choose between supporting individual autonomy and self-determination and preventing possible harm to the client or others.

Psychiatric advance directives (PADs) offer one strategy to reduce mandated interventions (Swanson, Swartz, Elbogen, et al., 2008). PADs are legal documents<sup>1</sup> that allow individuals to express their wishes for future treatment when, because of illness relapse, they may be incapable of doing so (Joshi, 2003). PADs are designed to be created while the individual is competent and go into effect during periods of decisional incapacity (Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006). Thus, PADs support individuals' autonomy and self-determination at a time when they are most vulnerable—when they are in crisis and cannot voice their preferences and needs because of their illness (Swanson, Tepper, Backlar, & Swartz, 2000). Beyond the connection between PADs and coercive interventions, PADs may also affect other clinical outcomes that may indirectly reduce crises and subsequent coercion. For example, PADs have the potential to improve treatment engagement, including working alliance, adherence, and service utilization, which may then affect crisis management, including early de-escalation of crises as an alternative to hospitalization, timely notification of clinician and family members regarding decomposition, or if hospitalization is required, improved inpatient management strategies.

PADs allow individuals to state treatment preferences through an advance instruction (AI) and/or a health care power of attorney (HCPA). In an AI, individuals can accept or refuse certain medications, identify hospital preferences, and accept or refuse other treatments such as electroconvulsive therapy. AIs may also be used to provide information on ways to de-escalate crises, make additional requests for actions if hospitalized (e.g., contact a family member), and even agree to future hospitalizations. A HCPA (variously called a healthcare agent, proxy, or Durable Power of Attorney for Healthcare) lets individuals appoint a representative to make treatment decisions on the client's behalf (i.e., using substitute judgment for the client's known preferences) when the client is unable to do so (Appelbaum, 2004). In most states, PADs are valid until revoked; in some states PADs expire within a certain time period. PADs are valid for two years in Pennsylvania and Tennessee; PADs are valid for three years in Illinois, Ohio, Oregon, South Dakota, Texas (only for the AI, HCAs in Texas do not expire) and Utah; PADs are valid in Louisiana for five years. In most states, revocation can occur at any time as long as the client is not declared incompetent or incapable.

Given their ability to support autonomy and self-determination and the potential to decrease mandated interventions, PADs should be of great interest to social workers. However, little exists in the social work literature regarding PADs and social workers' knowledge of PADs appears limited. In a survey of 193 social workers only 5% reported being "very familiar" with AIs and only 15% reported being "very familiar" with HCPAs for mental health (Scheyett, Kim, Swanson, et al., 2008). The goal of this integrative review is thus to provide social workers with information on the promise and challenges of implementing PADs, including their history, relevance to social work practice, and empirical evidence related to prevalence and latent demand for PADs and outcomes associated with PADs.

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<sup>1</sup>Psychiatric advance directives (PADs) are one type of "advance statement" for mental health treatment. Others include Wellness Recovery Action Plans, Joint Crisis Plans, and Crisis Cards. Goals for documenting treatment preferences are somewhat similar [cf., Henderson et al., (2008). A Typology of Advance Statements in Mental Health Care. *Psychiatric Services*, 59(1), 63–71]; however, PADs are the only method that is legally binding on the mental health practitioner. (It is important to note that clinicians are not legally obligated to provide care that conflicts with standards of community care. We discuss this in the *Overriding PADs and community standards of care* section below.)

## Historical context of the development of PADs

At their most basic level PADs are a variation on medical advance directives (ADs) and are thus framed by relevant legal cases. Two cases that provided the foundation for ADs involved Karen Ann Quinlan ("*In Re Quinlan*," 1976) and Nancy Cruzan ("*Cruzan v. Missouri Department of Health*," 1990). Both the *Quinlan* and *Cruzan* decisions addressed informed consent and the right to consent to or refuse treatment. Also during the same year that the *Quinlan* decision was handed down, and beginning with California (i.e., the State's Natural Death Act), all states enacted advance directive statutes, including AIs, durable powers of attorney, or both (Meisel & Cerminara, 2005).

Karen Ann Quinlan was a 22-year-old in a chronic persistent vegetative state. Her family wished to discontinue the use of a respirator and thus end Ms. Quinlan's life. The New Jersey Supreme Court overturned a lower court's earlier ruling denying this request and sided with Ms. Quinlan's family. The court's decision acknowledged that patients have a fundamental and constitutional right to refuse treatment even if they are unable or incompetent to make that decision. The notion that this right extended to incompetent patients was based on three factors: self-determination, best interests and equality (Olick, 2004). This argument can be extended to considerations of patients' rights during periods of incapacity around mental health crises as well.

The Quinlan decision and its impact on informed consent and the right to refuse treatment also factored into the *Cruzan* decision, which was handed down over a decade later. In 1983, Nancy Cruzan was a 25-year-old patient who was left in a persistent vegetative state following an automobile accident. After a period of time with no improvement, Mrs. Cruzan's family attempted to have her feeding tubes removed. Their basis for this request was a prior conversation between Mrs. Cruzan and a friend in which Mrs. Cruzan indicated that she would not want to be kept alive via artificial means without hope of recovery. The Missouri Supreme Court dismissed this claim based on the requirement of informed consent. Given the basic tenets of informed consent (i.e., understanding the situation and prognosis; uncoerced and voluntary; and having the capacity to make reasoned judgments), the court ruled that Mrs. Cruzan could not have understood the risks or benefits of treatment based on a hypothetical situation. While the subsequent U.S. Supreme Court decision noted that competent adults have a constitutionally-protected liberty to refuse treatment, this same right was not extended to incompetent patients (or patients in a vegetative state) unless there was "clear and convincing evidence" of the patient's wishes. While the "clear and convincing" standard does not require written directives, it is much more difficult to meet the standard with only oral statements. The *Cruzan* case thus had implications for the use of written directives and authorization of proxy decision-makers, and eventually led to the passage of the federal Patient Self-Determination Act (PSDA). The PSDA requires hospitals and other health care organizations that receive federal support to inform patients of their rights to prepare an advance directive, to inquire and document whether patients have executed a directive, to ensure compliance with state laws by respecting directives, and to educate health care providers regarding these legal instruments.

While both *Quinlan* and *Cruzan* proved important for the development of ADs, including PADs, these cases also helped to develop bioethical theory and treatment models for incapacitated patients. The application to the treatment of persons with SMI can be traced back to the 1970s when Paul Appelbaum, in response to an editorial on Michigan's House Bill 4058, which addressed living wills, wrote in the *New England Journal of Medicine*, "The idea's undoubted appeal in medical settings is exceeded only by its potential utility on the psychiatric ward" (Appelbaum, 1979, p. 788). Appelbaum then stated:

...the appointment of a surrogate to give a proxy consent for treatment when physicians attest that the patient's psychosis has recurred, is clearly an attractive one at this time. It would permit rational treatment based on the patient's own rational wishes (p. 788).

Shortly after this, Thomas Szasz proposed the concept of a "psychiatric will" as a means to avoid unwanted mental health treatment. Szasz's reasons for advocating means to avoid psychiatric treatment were grounded in his belief that mental illness is illusory (Szasz, 1997); for Szasz, if conventional psychiatric treatment was bad, then unwanted, or mandated, treatment was even worse -- and legally unjustified. Thus, in Szasz's view, persons should be legally empowered to forego such interventions. Other scholars have advanced similar critiques of social control and coercive interventions in mental health services (cf., Foucault, 1965; Horwitz, 1981) and these critiques helped fuel interest in PADs (Swanson, et al., 2000). The concepts of patient empowerment and patient-centered care provided other compelling reasons for supporting PADs.

Arising from the recovery movement, empowerment in mental health services (Anthony, 1993) remains an integral part of the rationale for PADs (Backlar, McFarland, Swanson, & Mahler, 2001). In this context, empowerment is viewed as exerting control over multiple domains of one's life (Rappaport, 1987). However, empowerment is also best viewed as multi-determined and derived from both internal (e.g., behavioral) and external (e.g., organizational) factors. An illustrative approach to the use of empowerment in mental health services can be seen in statements from Virginia's Commission on Mental Health Law Reform. Specifically, the Commission states that in order to "Facilitate engagement and *empowerment* (emphasis added) of persons" with SMI there should be an (1) emphasis on *individual choice* (emphasis added) in mental health statutes, regulations, policies and practices, which would include the (2) use of *crisis plans* and *advance directives* (emphasis added) in the event of impaired decisional capacity and make discussion of such plans a standard part of treatment, while promoting and respecting consumer choice (Commission on Mental Health Law Reform, 2007). Thus, empowerment respects individual choice while also recognizing the importance of factors external to the client; relevant to the development of PADs, empowerment is supported by patient-centered care.

Patient-centered care (PCC) has been illustrated in many ways since Enid Balint described the concept 40 years ago (Balint, 1969). Some of the more common ways in which PCC has been described include a style of communication between provider and patient (Ong, de Haes, Hoos, & Lammes, 1995), a way of a provider attempting to enter the world of the patient (McWhinney, 1989), or utilizing the patient's expertise to facilitate collaborative decision-making (Grol, de Maeseneer, Whitfield, & Mokkink, 1990). Perhaps the most cogent description of PCC comes from Stewart and colleagues in which they focus on six interrelated concepts: (1) exploring both the disease and the illness experience; (2) understanding the whole person; (3) finding common ground regarding illness management; (4) incorporating prevention and health promotion; (5) enhancing the provider-patient relationship; and (6) being realistic about limitations and issues such as the availability of time and resources (Stewart, Brown, Weston, et al., 1995). The interaction of these concepts has subsequently been conceptualized as representing a model of PCC in which five dimensions exist: (1) patient-as-person; (2) clinician-as-person; (3) shared power and responsibility; (4) therapeutic alliance; and (5) biopsychosocial model of health and illness (Mead & Bower, 2000). While the notion of PCC, including a reliance on the biopsychosocial model (Engel, 1977) is certainly not new to social workers (Johnson, Atkins, Battle, et al., 1990) there has been little attention paid to the ethical imperative that social workers have towards these tenets in their work with mental health consumers.

While social workers are a vital component of the mental health delivery system (Manderscheid & Henderson, 2003) for some of society's most vulnerable adults, it is also true that social workers have struggled with balancing empowerment and clinical power in treatment settings (Encandela, Korr, Lidz, Mulvey, & Slawinski, 1999; Odiah, 2004). For example, research suggests that social workers believe clients with impaired decision-making capacity would benefit from paternalistic interventions (McCubbin & Cohen, 2003). Additionally, social workers practicing in the public sector report using warnings regarding directive interventions (e.g., regarding hospitalization, money, etc) to improve adherence with treatment more than those not working in the public sector (Scheyett, Kim, Swanson, et al., 2009). While social workers in public mental health settings have a difficult endeavor in balancing empowerment and restrictions, the Profession's Code of Ethics provides insight into these issues that are of particular relevance to PADs.

## Relevance of PADs to social workers

While arguments for PCC in mental health services are supported by concepts like empowerment, parity, patient rights and effectiveness (Tomes, 2006), social work's values and ethics can also serve as a guiding framework for understanding PADs. Specifically, PADs underscore the importance of two of the Profession's ethical principles: (1) *Social workers respect the inherent dignity and worth of the person* and (2) *Social workers recognize the central importance of human relationships* (National Association of Social Workers, 1996). With regard to the former, social workers are charged to, "respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals." This principle can be linked to empowerment and autonomy, both of which are central to psychosocial rehabilitation and recovery, in addition to PADs (Elbogen, Swanson, Swartz, et al., 2007; Scheyett, Kim, Swanson, & Swartz, 2007). The latter principle states that "social workers understand that relationships between and among people are an important vehicle for change. Social workers engage people as partners in the helping process." This concept is tied to PCC through a bi-directional flow of information in which both the clinician and client have active roles in discussing preferences, risks, benefits and treatment options (Hamann, Leucht, & Kissling, 2003).

PADs also support another element of social work practice, the strengths perspective, which requires that social workers see individuals "in light of their capacities, talents, competencies...values and hopes" and that social workers consider "what people know and what they can do" in addition to their challenges (Saleebey, 1996, p. 297). A core principle of the strengths perspective is that interventions are based on client self-determination (Rapp, 1998). PADs are grounded in the belief that SMI individuals, when competent, can identify treatments that are most helpful to them, that they know what they need, and that it is important to honor their values, even during times when they cannot convey their wishes.

Beyond the ethical imperative to consider PCC and the congruence between PADs and social work models, such as the strengths model, the fact that social workers are one of the primary treatment providers for individuals with SMI is another reason to educate social workers about PADs. As a profession, social work represents one of the largest (Manderscheid & Henderson, 2003) and still growing (Mechanic & Bilder, 2004) provider-groups of mental health services in the United States; additionally, for most social workers, the provision of mental health services continues to be the main draw to the profession (Gibelman, 2004). Social workers also provide treatment to a large proportion of clients with SMI in the public mental health system (Offer, 1999), which is a targeted population for PADs. Thus, it is important that social workers understand PADs and also become aware of emerging PADs research and its implications for practice.

## Prior research on PADs

Our review of prior research on PADs consisted of comprehensive searches of several databases (i.e., PubMed, Social Service Abstracts, Social Sciences Citation Index, Social Work Abstracts, PsychInfo, Medline). Search strategies utilized the following main key words: psychiatric, mental illness, advance directive, advance instruction. The following adjunct key words were also used: prevalence, demand, attitudes, barriers, competence, facilitation, override, preempt, crisis, outcome. Main key words were used in combination with the adjunct key words. Article abstracts were examined and articles based on original data collection were reviewed and categorized into common areas as summarized below. The areas are presented in a manner that conveys a somewhat linear research history. This includes research findings related to prevalence and demand for PADs, attitudes towards PADs, barriers to completing PADs, including competence, efforts to facilitate PAD completion, overriding PADs, and outcomes associated with PAD completion.

### Prevalence and demand

The “real-world” uptake of PADs has been limited, despite the impetus of the PSDA, PAD legislation in 25 states, and the fact that all states allow advance statements for mental health in their health care decisions laws. Four studies have examined the prevalence of or demand for PADs<sup>2</sup>. In a sample of 303 persons with SMI and a history of crisis service use, 53% of subjects expressed an interest in completing a PAD (Srebnik, Russo, Sage, Peto, & Zick, 2003). Two studies assessed both latent demand for and prevalence of PADs. The first study included 104 persons with SMI while the second study included 1,011 persons with SMI in five U.S. cities. In the former study, 7% of participants had completed a PAD; however, 67% indicated an interest in completing one (Swanson, Swartz, Hannon, et al., 2003). In the latter study, between 4 and 13% of subjects across study sites had completed a PAD; however, between 66 and 77% of participants wanted to complete one (Swanson, Swartz, Ferron, et al., 2006). In a study conducted in England, 40% of participants (N=106) wanted to complete a crisis card (Sutherby, Szmukler, Halpern, et al., 1999), which has similarities to PADs (Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008). Clearly, persons with SMI are interested in PADs; however, actual rates of completion remain low.

Many factors affect mental health consumers’ willingness to complete a PAD. One study found that higher demand for PADs was present among females, nonwhites and those with a history of self-harm, arrest, and decreased personal autonomy, including those who felt pressured to take medication (Swanson, Swartz, Ferron, et al., 2006). Another study found that case managers’ support for PADs was associated with desire to complete a PAD. Contrary to the former study, this latter study found greater interest in PAD completion among those with no recent directive intervention (i.e., outpatient commitment) (Srebnik, et al., 2003).

### Other stakeholders’ knowledge of and attitudes towards PADs

While prior research indicates that consumers of mental health services have a strong latent desire for PADs, other stakeholders, including clinicians and family members of persons with mental illness appear to be more mixed in their views of PADs. In a study of almost 600 clinicians, including social workers, psychiatrists and psychologists, less than half of the sample (47%) endorsed AIs as potentially helpful to persons with SMI. The sample expressed a more favorable view of HCPAs, which were endorsed by 57% of the sample

<sup>2</sup>In another study (N=156), 41% and 26% of family members or clinicians knew someone that had an AI or an HCPA, respectively (Backlar & McFarland, 1996). However, the prevalence cannot be calculated as the denominator (e.g., for the clinicians, the *total* number of clients on one’s case load) was not available.

(Elbogen, Swartz, Van Dorn, et al., 2006). (However, social workers were significantly less likely than the other professional groups to approve of the laws supporting PADs as potentially beneficial.) In this same research, regardless of profession, attitudes towards PADs were more positive when respondents were aware of state laws allowing clinicians to override advance instructions that conflict with community practice standards.

In other research assessing clinicians' (N=85, of which 30% held a Master of Social Work degree) experiences with PADs, only a small proportion (13%) reported having a client with either type of PAD document (Swanson, et al., 2003). However, the clinicians were virtually unanimous (96%) in their support of clients completing a PAD if provided assistance. Clinicians' effusive support of PADs was based on their belief that PADs would make consumers feel more empowered. The notion of empowerment as a principal reason for advocating PAD completion appears to be where clinicians and other stakeholders, including clients and family members, differ in their reasons for supporting PADs.

Family members' and consumers' support for PADs is tied to proscriptive and prescriptive functions of PADs (Swanson, et al., 2003). For example, 77% of persons with SMI and 72% of their family members indicated that it was important to have a PAD to avoid being treated against one's will. In contrast, 28% of surveyed clinicians endorsed PADs for this reason. Similar findings were present for the prescriptive function of PADs. Specifically, 87% of consumers indicated that PADs were necessary to avoid going without needed treatment. By comparison, 72% of family members and 51% of clinicians endorsed PADs to ensure obtaining needed treatment. All between-group comparisons were statistically significant (Swanson, et al., 2003).

Research suggests that family members of those with a mental illness strongly support PADs in general, particularly the HCPA mechanism. In prior research, 95% of family members endorsed the HCPA component of PADs whereas 79% and 80% of consumers and clinicians did the same; these between-group differences were statistically significant (Swanson, et al., 2003). While prior research indicates that all mental health stakeholder groups have interest in, and high hopes for PADs, this same research indicates that substantial barriers may prevent successful completion and utilization of PADs.

### **Barriers to completing and utilizing PADs**

Barriers to PADs represent perhaps the greatest challenge to PADs as intended. These barriers are multifaceted and include those related to clinicians' ability or willingness to implement the documents and consumers' ability to complete the documents (O'Connell & Stein, 2005). The attitudes of clinicians toward PADs are critical at two points in time: the preparation stage, when an individual with SMI creates the PAD; and the implementation stage, when a PAD is invoked during a mental health crisis. In the preparation stage, the utility of clinicians' involvement is still under debate (Peto, Srebnik, Zick, & Russo, 2004; Srebnik & La Fond, 1999; Varekamp, 2005); however, evidence points to a positive relationship between clinicians' support of PADs and consumers' interest in them (Srebnik, et al., 2003). Clinicians' lack of support for PADs could represent a barrier to PAD preparation as it is believed that most consumers need some support to complete PADs (Peto, et al., 2004). Clinicians' attitudes regarding the implementation of PADs are also likely to come into play when presented with a PAD during a mental health crisis, as the implementation is the clinician's responsibility and their attitudes may affect what they do (if anything) to make PADs work as designed. Clinicians report barriers related to the operational features of the work environment, including a lack of communication between staff and lack of access to the document. Clinicians also describe barriers related to clinical or treatment factors, including consumers' potential inappropriate treatment requests and desires to change their mind about treatment during crises; however, barriers related to the

work environment were endorsed at a higher rate than those related to clinical factors (Van Dorn, Swartz, Elbogen, et al., 2006). While clinicians have identified concerns that affect their willingness to support the completion of PADs or their implementation during a crisis, consumers have also identified multiple factors that make it difficult to complete PADs.

Given the evidence of consumers' interest in PADs but low rates of PAD completion, it is apparent that significant barriers are preventing consumers from taking advantage of PADs. These barriers include a misunderstanding of PADs; lack of resources necessary to complete PADs; lack of someone to serve as proxy decision maker; inability to navigate the complexity of the PAD documents, including obtaining witnesses, notarization, and filing the documents in a medical record or registry. Prior research highlights the need for consumer education and assistance with PADs; for example, a majority of consumers (77%) indicated that they did not understand enough about PADs to complete one on their own (Swanson, et al., 2003). In a sample of 462 persons with SMI, approximately three quarters of the participants reported barriers related to the PAD documents (i.e., not knowing what to write or not understanding the documents) whereas one-third of participants identified barriers associated with external support for PADs (i.e., having no one they trust to make decisions, or an inability to get information from one's clinician about what to include in the PAD) (Van Dorn, Swanson, Swartz, Elbogen, & Ferron, 2008). In addition to the above barriers, illness processes including cognitive impairment in persons with SMI may hinder PAD completion.

### **Competence and PADs**

Competence is a principal component of both PAD completion and implementation. Specifically, clients must be competent when they prepare, sign and have the PAD notarized (Srebnik, Appelbaum, & Russo, 2004). In this context, competence refers to the capacity to both make and write the decisions identified in the PAD. While it is legally assumed that persons with mental illness are competent to complete PADs, some ethicists claim that future-oriented instructions are a poor substitute for the current choices of a competent individual (Brock, 1993; Dresser, 1989). (Only two states, however, require a clinician to endorse a PAD: In Indiana the treating psychiatrist must sign the instructions, indicating that the treatment choices are "appropriate" and that the client was competent at the time the document was created. Additionally, in Indiana one must appoint an HCPA. In Louisiana either a physician or psychologist must attest to the client's "ability to make reasoned decisions" about treatment at the time the document was completed.) Clinicians' perspectives on this are clear; one survey found that 90% of clinicians would be more likely to support directives if a clinician endorsed the client's competence at the time the document was completed (Srebnik & Brodoff, 2003). However, it should be noted that the same desire for demonstrated competence is not present for the completion of medical advance directives.

### **PAD facilitation**

While consumers' barriers to PAD completion and clinicians' concerns regarding PAD creation and implementation are well documented, interventions have shown the ability to increase rates of PAD completion. For example, a randomized trial demonstrated that a structured facilitation can significantly increase PAD completion rates. Specifically, 61% of persons with SMI randomly assigned to the facilitation completed an AI or authorized an HCPA compared to only 3% of those assigned to the usual-care condition (Swanson, Swartz, Elbogen, et al., 2006). Research utilizing these same data indicated that the facilitation reduced barriers related to both the PAD documents themselves and external support for PADs over the course of one year. The reduction of the barriers was an



important mechanism by which the intervention resulted in completed PADs (Van Dorn, et al., 2008).

The facilitated intervention described above utilized a semistructured, manualized interview; the process was facilitated by trained research assistants. However, other research has utilized a computer assisted program (AD-Maker) to facilitate PAD completion (Sherman, 1998). An early study for AD-Maker found that a majority of randomly selected persons with SMI were able to complete an psychiatric advance statements within 80 minutes and that the computer program, which used drop-down menus for choices, was an effective way to complete the PAD, even for those with little to no prior computer experience (Sherman, 1998). AD-Maker has been used subsequently in a study with persons with two or more psychiatric hospitalizations within two years (Srebnik, Rutherford, Peto, et al., 2005). However, research from this latter study found that when using AD-Maker, older adults needed more technical support--i.e., with the computer program--than did younger participants (older adults were also in need of more non-technical support--i.e., phrasing instructions) (Peto, et al., 2004).

### Overriding PADs and community standards of care

Given the already discussed concerns about competence and PADs, it is relevant to briefly discuss the possibility of clinicians overriding PADs during a crisis and whether or not completed PADs conform to community standards of care. All advance directive, or PAD-specific, statutes for mental health allow the clinician to override patients' advance choices for treatment when the preference conflicts with standards of care and the clinician is acting in good faith; however, when this happens, clinicians in most situations are obligated to follow whatever portions of the PAD they can, even if they override specific instructions (Swanson, McCrary, Swartz, Elbogen, & Van Dorn, 2006). Because there have been relatively few PADs created it is difficult to determine what factors predict clinicians "real life" proclivities to override PADs. However, in response to a hypothetical vignette, 47% of surveyed psychiatrists indicated that they would override a valid, competently-executed PAD that refused hospitalization and medication. PAD-override was more likely among psychiatrists who worked in hospital emergency departments; those who were concerned about patients' violence risk and lack of insight; and those who were legally defensive. PAD override was *less* likely among participants who believed that involuntary treatment is largely unnecessary in a high-quality mental health system (Swanson, et al., 2007).

Prior research has also examined completed PADs for adherence to community standards of care and found that the PADs were overwhelmingly consistent with these tenets (Srebnik, et al., 2005; Swanson, Swartz, Elbogen, et al., 2006). In one study, medication and hospital preferences were rated by psychiatrists as consistent with community practice standards and both feasible and consistent 90% and 83% of the time, respectively (Swanson, Swartz, Elbogen, et al., 2006). In other research that examined 106 completed PADs, 16 of 17 factors were rated as consistent with community standards of care 96% of the time or more. The only factor that was not rated as highly in this latter review was willingness to try medications not listed in the directive, which was consistent with standards of care 57% of the time (Srebnik & Russo, 2007). In both of these studies, which reviewed over 340 completed PADs--either AIs or HCPAs--no document refused *all* treatment. While clinicians are worried about being presented with PADs that do not allow them to treat patients, the empirical evidence does not bear this out. (For a different perspective on this, see a recent decision by the U.S. Court of Appeals for the 2nd Circuit, which struck down a state law that allowed mental health professionals to override a person's advance refusal of psychotropic medications through a general health care proxy ("*Hargrave v Vermont*, 340 F. 3d 27," 2003)).

## PAD outcomes

To this point, the reviewed evidence indicates that PADs are valued by mental health stakeholder groups, albeit for somewhat different reasons; still, the uptake of PADs remains minimal as multiple barriers hinder their completion and implementation. However, interventions can reduce these barriers and increase rates of PAD completion. Finally, when PADs are completed the information contained therein is useful and consistent with community standards of care. In addition, recent studies are showing that PADs also improve clinical outcomes for those who complete them. For example, interventions designed to facilitate completion of PADs can improve treatment satisfaction, working alliance and competence to make treatment decisions (Elbogen, Swanson, Appelbaum, et al., 2007; Swanson, Swartz, Elbogen, et al., 2006). Other research indicates that PADs were able to reduce the use of coercive crisis interventions (e.g., being transported by the police for psychiatric treatment or evaluation; being involuntarily committed to a hospital) over the course of two years (Swanson, et al., 2008). Other studies have come to similar conclusions. A study in the United Kingdom that examined Joint Crisis Plans (JCPs), which have similar goals to PADs, but without the document being legally binding on the mental health provider (Henderson, et al., 2008), found that the use of coercive interventions were significantly reduced over time. Additionally, there were fewer instances of violence for those with JCPs than those without (Henderson, Flood, Leese, et al., 2004). Another study in the UK, however, found no significant differences between a group randomly assigned to complete a PAD and those randomized to usual care in rates of involuntary readmission, inpatient days, or satisfaction with psychiatric services (Papageorgiou, King, Janmohamed, Davidson, & Dawson, 2002). In another study, the authors found that when PADs were accessed during a mental health crisis, two-thirds of subsequent treatment decisions were consistent with them; yet, PADs were only accessed for 20% of crisis events. This same study noted that there were low rates of consultation with proxy decision makers during crises; although when proxies were “involved” the PAD was significantly more likely to be accessed (Srebnik & Russo, 2008). While *in toto* these findings show promise, this latter finding regarding the lack of involvement of proxies is concerning as their involvement is seen as important for successful PAD implementation (Backlar, 1997). Finally, qualitative research has attempted to describe, from the consumer’s experiential perspective, some of the strengths and limitations of PADs as actually used, or not used, during mental health crises (Kim, Van Dorn, Scheyett, et al., 2007).

## Critique of prior research on PADs

Though initial studies are promising, there are several areas where research remains lacking. Specifically, there is little research that follows consumers for extended periods of time to assess the long-term impacts of PADs (the outcome studies reviewed above followed people for one or two years). Longitudinal studies are needed over multiple years to determine the effectiveness of PADs in decreasing crises, increasing connection with treatment, and improving recovery in consumers with SMI. A cost-benefit analysis component of these long-term follow-up studies should be included as well.

A second area of need involves the contextualization of PAD effectiveness within the larger service system. The literature has highlighted provider concerns regarding PADs, including logistical barriers to accessing and sharing the information available in PADs. If PADs are to be effective the service system must support their creation, access, and utilization. However, PAD outcome studies have traditionally lacked this contextual focus. Little research exists on effective ways to overcome barriers to access and utilization of PADs, including comparing ways to ensure that PADs are able to be accessed at any time (e.g., Living Will Registries, medical-alert bracelets, state registries, filing PADs with likely inpatient destinations, etc). Empirically tested interventions are needed to educate and

improve provider attitudes regarding PADs so that they may support PAD creation and utilization. Systemic interventions are needed to develop effective and timely ways to share PAD information when a consumer is in crisis. Communication systems involving both staff training and technology utilization could be promising, but have yet to be rigorously explored.

Third, prior PAD research lacks consumer voice. It is ironic that, though PADs are tools for consumer empowerment and autonomy, consumers have had little involvement in PAD research. Future PAD research would benefit from a participatory action research approach (Atweh, Kemmis, & Weeks, 1998), and research in partnership with the consumer advocacy community is needed.

Fourth, various methods of declaring advance statements should be examined. For example, do JCPs, which differ from PADs in that (1) clinicians are not legally obligated to follow the client's declarations; and (2) they are predicated on direct involvement of the client's primary clinician in helping create the document, which is not a requirement of PADs, lead to better outcomes for some clients compared to others (e.g., persons with severe mental illness who are distrusting of legal documents)?

Fifth, there has been little research into the stability of preferences, particularly for advance consent decisions, errors in HCA-decisions, and cognitive biases in predicting satisfaction with future psychiatric treatment choices. All of these "affective forecasting" issues are relevant to PADs and should be explored, including whether or not errors in affective forecasting lead to disappointment with PADs and with what consequence.

Sixth, and finally, little research has explored PADs in the context of race and culture (Van Dorn, Swanson, & Swartz, In-Press). There has been little effort to disaggregate racial and ethnic groups beyond traditional White/non-White designations when considering desire for or actual PAD uptake. Additionally, there have been few attempts to explore emic representations of PADs from consumers' or HCPAs' perspectives, which might improve the understanding of PADs, particularly for racial and ethnic minorities, a group that has traditionally been disenfranchised from, or had little voice in, mental health care (Lefley, 1990). This same need to understand PADs at a more nuanced level is also related to sex and age differences for persons with SMI.

## **Future research and practice agenda for social workers**

Social work can make unique contributions to both research and practice regarding PADs. Social work's dual focus on individual need and social justice expands the traditional medico-legal model to examine both clinical impact and rights from a systems perspective. Social work is well positioned to examine the effectiveness of PAD interventions across a range of contexts—for example how effective are PADs for individuals from non-majority groups or cultures? How might membership in multiple oppressed groups (e.g., SMI and gay/lesbian or SMI and racial minority) affect the impact of PADs?

As discussed above, research is lacking in ways to overcome barriers to PAD utilization. In addition to social work research on PADs within the context of clients' lives, experiences, and environments, social work research should address these barriers to PAD implementation. This too should be done from a systems and social justice/anti-oppression perspective. Effective interventions need to be developed and tested to ensure that social workers are knowledgeable about PADs, are willing and able to honor PADs, and work within systems where PADs can be implemented.

In addition to research, studies suggest that social workers are in need of education regarding PADs, which has implications for social work education. Inclusion of PAD content in the social work curriculum is needed. PAD content is appropriate for courses addressing services to adults with mental illness and should include an understanding of what PADs are and how they support the principles in the Code of Ethics. Additionally, this content should emphasize patient centered care within the context of a therapeutic alliance, which would provide an overview of the clinical skills needed to engage consumers in the discussion of whether or not to prepare a PAD. PAD content is also needed in mental health policy and advocacy courses and trainings, linked with other policies protecting the rights of individuals with mental illnesses. PADs should be discussed as both a clinical crisis planning tool *and* a tool for social justice. Social workers should therefore be educated in effective ways to inform consumers about their rights to a PAD, and social workers should also be educated as to their role in ensuring that the client's PAD is made available and honored within community standards of care during mental health crises. This role will require skill building in the area of advocacy and negotiating for the invocation and implementation of PADs within settings where traditional medical models are a more common framework than social work's social justice/psychosocial approach.

The literature also indicates a lack of awareness of PADs among already practicing clinicians, thus education on PADs should move beyond the social work curriculum and include continuing education on PAD content. Social work supervisors play a central role in PAD education efforts and can encourage attendance at workshops, provide staff access to information and materials on PADs<sup>3</sup>, and discuss PAD utilization with trainees during supervision. For already practicing clinicians it is critical that social workers leverage their work with family members of those with SMI, in both inpatient and outpatient settings, to educate all involved parties about PADs. When viewed from this context, no other mental health professional group could have a larger impact on advancing multiple aspects of PADs. An important new resource providing PAD information that can begin to facilitate these next steps is the National Resource Center on Psychiatric Advance Directives, which is a collaborative effort between the Bazelon Center for Mental Health Law and the Department of Psychiatry and Behavioral Sciences, Duke University Medical Center ([www.nrc-pad.org](http://www.nrc-pad.org)).

In sum, individuals with SMI are a vulnerable, stigmatized, and often voiceless group of people who experience both painful psychiatric symptoms and sometimes iatrogenic effects of involuntary treatment. PADs are legal instruments that have the potential to both improve clinical outcomes and decrease involuntary interventions. Social workers can play a major role in the use of PADs, which may increase consumer engagement with the mental health system, improve the care that consumers receive, decrease crises and coercive care, and increase consumer empowerment and recovery.

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<sup>3</sup>For example, the DVD, "Crisis and Control: What's the Role of Psychiatric Advance Directives" could be utilized in classroom, practicum, or clinical settings. (See <http://www.unlistedfilm.com/crisis.html> for more information.)

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