Psychiatric advance directives and social workers: an integrative review.
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Individuals with severe mental illness (SMI) 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, many people with SMI describe such interventions as frightening, disempowering, traumatic, and a barrier to treatment (Swartz, Swanson, & Hannon, 2003; Van Dorn, Elbogen, 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 et al., 2008). PADs are legal documents that allow individuals to express preferences for future treatment (Joshi, 2003) and 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). (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 preferences are somewhat similar [compare, Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008]; however, PADs are the only method that is legally binding on the clinician, but clinicians are not legally obligated to provide care that conflicts with community practice standards. We discuss this in the Overriding PADs and Community Standards of Care section.) PADs support individuals’ autonomy and self-determination when they are in crisis and cannot voice their preferences and needs because of their illness (Swanson, Tepper, Backlar, & Swartz, 2000). PADs may also affect clinical outcomes that indirectly reduce crises and coercion. For example, PADs have the potential to improve treatment engagement, adherence, and service utilization, which may then affect crisis management, including deescalation of crises as an alternative to hospitalization, timely notification of clinicians and family members regarding decomposition, or (if hospitalization is required) improved inpatient management strategies.

PADs can include an advance instruction (AI) or a healthcare power of attorney (HCPA). In an AI, individuals can accept or refuse certain medications or other treatments (for example, electroconvulsive therapy) and identify hospital preferences. Als may also be used to provide information on ways to deescalate crises, make requests for actions if hospitalized (for example, contact a family member), and agree to future hospitalizations. An HCPA (variously called a "healthcare agent," "healthcare proxy," or "durable power of attorney for health care") lets individuals appoint a representative to make treatment decisions on their behalf (that is, using substitute judgment for the client’s known preferences) when they are unable to do so (Appelbaum, 2004). In most states, PADs are valid until revoked, which can occur at any time as long as the client is not declared incompetent or incapable; in some states, PADs expire within a certain time period (for example, two years in Pennsylvania, three years in Oregon, five years in Louisiana).

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 percent reported being "very familiar" with AIs, and only 15 percent reported being "very familiar" with HCPAs for mental health (Scheyett et al., 2008). The goal of this integrative review is thus to provide social workers with information on the promises and challenges of implementing PADs, including their history, their relevance to social work practice, and the empirical evidence related to prevalence and latent demand for PADs and outcomes associated with PADs.

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, including In Re Quinlan (1976) and Cruzan v. Director, 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 (that is, the state’s Natural Death Act [codified as California Health & Safety Code [section]7185-7195]), 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 her life. The New Jersey Supreme Court overturned a lower court's ruling denying this request and sided with Ms. Quinlan's family. The court's decision acknowledged a patient's right to refuse treatment even if the patient is unable or not competent 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)--and it can be extended to considerations of patients' rights during periods of incapacity around mental health crises as well.

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, Ms. Cruzan's family attempted to have her feeding tubes removed on the basis of a prior conversation between Ms. Cruzan and a friend in which Ms. Cruzan indicated that she would not want to be kept alive through artificial means without hope of recovery. The Missouri Supreme Court dismissed this claim on the basis of the requirement of informed consent. Given the basic tenets of informed consent (that is, capacity to understand, consent being uncoerced and voluntary, and capacity to make reasoned judgments), the court ruled that Ms. Cruzan could not have understood the risks or benefits of treatment on the basis of a hypothetical situation. Although the subsequent U.S. Supreme Court decision noted that competent adults have a constitutionally protected right 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. Although the "clear and convincing" standard does not require a written directive, it is much more difficult to meet this standard with only oral statements. The Cruzan case thus had implications for the use of written directives and authorization of proxy decision makers, and it eventually led to the passage of the federal Patient Self-Determination Act (PSDA) (Omnibus Budget Reconciliation Act of 1990). The PSDA requires healthcare organizations that receive federal support to inform patients of their rights to prepare a directive, to document whether patients have executed a directive, to comply with state laws regarding directives, and to educate providers regarding these legal instruments.

The application of ADs to people with SMI can be traced to the 1970s, when Paul Appelbaum--in response to an editorial on a pending bill in Michigan's House of Representatives, 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 Appelbaum's letter, the concept of a "psychiatric will" was proposed as a means to avoid unwanted mental health treatment (Szasz, 1982). Other scholars have also advanced critiques of social control and coercive interventions in mental health services (see, Foucault, 1965; Horwitz, 1981), and these critiques helped fuel interest in PADs (Swanson et al., 2000). Patient empowerment and patient-centered care provided other compelling reasons to support PADs.

Empowerment is viewed as exerting control over multiple domains of one's life (Rappaport, 1987), is derived from both internal (for example, behavioral) and external (for example, organizational) factors, and is an integral part of the rationale for PADs (Backlar, McFarland, Swanson, & Mahler, 2001). An instructive approach to the use of empowerment in this context can be seen in statements from Virginia's Commission on Mental Health Law Reform (2007): The Commission states that in order to "facilitate engagement and empowerment of persons [italics added]" with SMI, there should be an emphasis on individual choice in mental health statutes, regulations, policies, and practices, which would include the use of crisis plans and advance directives in the event of impaired decisional capacity and make discussion of such plans a standard part of treatment. Thus, empowerment respects individual choice while also recognizing the importance of factors external to the individual; relevant to the development of PADs, empowerment is supported by patient-centered care (PCC).

PCC has been illustrated in many ways since Balint (1969) described the concept 40 years ago. Perhaps the most cogent description of PCC came from Stewart et al. (1995), who focused 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. The interactions of these concepts have been conceptualized as follows:
patient-as-person, clinician-as-person, shared power and responsibility, therapeutic alliance, and biopsychosocial model of health and illness (Mead & Bower, 2000). Although the notion of PCC, including a reliance on the biopsychosocial model (Engel, 1977), is certainly not new to social workers (Johnson et al., 1990), little attention has been paid to the ethical imperative that social workers have toward these tenets in their work with mental health consumers.

Although 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 (Odiah, 2004). Research suggests that social workers believe that clients with impaired decision-making capacity will benefit from paternalistic interventions (McCubbin & Cohen, 2003). In addition, social workers practicing in the public sector report using warnings regarding directive interventions (for example, hospitalization, money) to improve adherence with treatment more than do those not working in the public sector (Scheyett et al., 2009). Although social workers in public mental health settings have a difficult endeavor in balancing empowerment and restrictions, the profession's Code of Ethics (NASW, 1996) provides insight into these issues that are relevant to PADS.

RELEVANCE OF PADS TO SOCIAL WORKERS

PADs underscore the importance of two of the profession's ethical principles (NASW, 1996): (1) "Social workers respect the inherent dignity and worth of the person" (p. 5) and (2) "Social workers recognize the central importance of human relationships" (p. 5). 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" (p. 7). This principle can be linked to empowerment and autonomy--both of which are central to psychosocial rehabilitation and recovery--in addition to PADS (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" (p. 6). This concept is tied to PCC through a bidirectional flow of information in which both the clinician and the client have active roles in discussing preferences, risks, benefits, and treatment options (Hamann, Leucht, & Kissling, 2003).

PADs also support 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 be based on client self-determination (Rapp, 1998). PADs are grounded in the belief that individuals with SMI, 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 them 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. 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 PubMed, Social Service Abstracts, Social Sciences Citation Index, Social WorkAbstracts, PsycINFO, and MEDLINE. We used the following main key words: psychiatric, mental illness, advance directive, and advance instruction. The following adjunct key words were also used: prevalence, demand, attitudes, barriers, competence, facilitation, override, preempt, crisis, and 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 in the following.

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. (In another study [N = 156], 41 percent and 26 percent of family members or clinicians knew someone who had an AI or an HCPA, respectively [Bacikar & McFarland, 1996]. However, the prevalence cannot be calculated because the denominator [for example, for the clinicians, the total number of clients on one's caseload] was not available.) In a sample of 303 people with SMI and a history of crisis service use, 53 percent 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 people with SMI, and the second included 1,011 people with SMI in five U.S. cities. In the first study, 7 percent of participants had completed a PAD; however, 67 percent indicated an interest in completing one (Swanson et al., 2003). In the second study, between 4 percent and 13 percent of participants across study sites had completed a PAD; however, between 66 percent and 77 percent of participants wanted to complete one (Swanson, Swartz, Ferron, et al., 2006). In a study conducted in England, 40 percent of participants (N = 106) wanted to complete a crisis card (Sutherby et al., 1999), which has similarities to a PAD (Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008). Clearly, people with SMI are interested in PADs; however, actual rates of completion remain low.

Many factors affect consumers' willingness to complete a PAD. One study found that higher demand for PADs was present among women; nonwhites; and those with a history of self-harm, arrest, and decreased personal autonomy, including feeling 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 PADs among those with no recent directive intervention (that is, outpatient commitment) (Srebnik et al., 2003).

Other Stakeholders' Knowledge of and Attitudes toward PADs

Although prior research indicates that consumers of mental health services have a strong latent desire for PADs, clinicians and family members of people 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 percent) endorsed AIs as potentially helpful to people with SMI; HCPAs were endorsed by 57 percent of the sample (Elbogen et al., 2006). In this same research, regardless of profession, attitudes toward PADs were more positive when respondents were aware of state laws allowing clinicians to override PADs that conflict with community practice standards (for example, directives refusing all medications would generally not be consistent with community practice standards for people with SMI, nor would directives requesting services that are unavailable in a local area).

In other research assessing clinicians' (N = 85, of which 30 percent held an MSW degree) experiences with PADs, only 13 percent reported having a client with either type of PAD document (Swanson et al., 2003). However, the clinicians were virtually unanimous (96 percent) in their support of clients completing a PAD if provided assistance. Clinicians' 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.

Clients and family members are significantly more likely than clinicians to endorse the importance of the proscriptive and prescriptive functions of PADs. For example, 77 percent of clients, 72 percent of family members, and 28 percent of clinicians endorsed the importance of having a PAD to avoid being treated against one's will. Similarly, 87 percent, 72 percent, and 51 percent of consumers, family members, and clinicians, respectively, indicated that PADs were necessary to avoid going without needed treatment (Swanson et al., 2003).

Research suggests that family members of those with a mental illness strongly support PADs, particularly the HCPA mechanism. Family members were significantly more likely to endorse HCPAs than were either consumers or clinicians (95 percent versus 79 percent and 80 percent, respectively) (Swanson et al., 2003). Although 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 use of PADs.

Barriers to Completing and Using PADs

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Barriers to PADs represent perhaps the greatest challenge to PADs as intended and include factors related to clinicians' ability or willingness to implement PADs and consumers' ability to complete the documents (O'Connell & Stein, 2005). Clinicians' attitudes toward PADs are critical at two points in time: when the PAD is created and when the PAD is invoked during a crisis. The utility of clinicians' involvement in the preparation stage is still under debate (Peto, Srebnik, Zick, & Russo, 2004); 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 they are presented with a PAD during a crisis, because implementation is the clinicians' 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 access to the document. Clinicians also describe barriers related to clinical factors, including consumers' potential inappropriate treatment requests; however, barriers related to the work environment were endorsed at a higher rate than those related to clinical factors (Van Dorn, Swartz, et al., 2006). Consumers have also identified multiple PAD-related barriers.

Given 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, having the documents notarized, 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 percent) indicated that they did not understand enough about PADs to complete one on their own (Swanson et al., 2003). In a sample of 462 people with SMI, three-quarters of the participants reported barriers related to the PAD documents (for example, not understanding the documents), whereas one-third identified barriers associated with external support for PADs (for example, having no one they trust to make decisions) (Van Dorn, Swanson, Swartz, Elbogen, & Ferron, 2008). In addition to the above barriers, illness processes, including cognitive impairment in people with SMI, may hinder PAD completion.

Competence and PADs

Competence is a principal component of PADs. 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. Although it is legally assumed that people 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; an HCPA must also be appointed. 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.) One survey found that 90 percent 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

Although 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 percent of people with SMI randomly assigned to a facilitation completed an AI or authorized an HCPA, compared with only 3 percent of those assigned to a usual-care condition (Swanson, Swartz, Elbogen, et al., 2006). Research using 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, Swanson, Swartz, Elbogen, & Ferron, 2008).

The facilitated intervention just described used a semistructured, manualized interview; the process was facilitated by trained research assistants. However, other research has used a computer-assisted program (AD-Maker) to facilitate PAD completion (Sherman, 1998). An early study using AD-Maker found that a majority of randomly selected people with SMI were able to complete a psychiatric advance statement within 80 minutes and that the computer program, which used drop-down menus for choices, was an effective way
to complete the statement, even for those with little or no prior computer experience (Sherman, 1998). AD-Maker has been used subsequently in a study with people with two or more psychiatric hospitalizations within two years (Srebnik et al., 2005). However, research from this latter study found that when using AD-Maker, older adults needed more technical support--that is, with the computer program--than did younger participants (older adults also needed more non-technical support--that is, 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 completed PADs conform to community standards of care. All advance directive, or PAD-specific, statutes for mental health allow clinicians to override patients’ advance choices for treatment when a 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, et al., 2006). Because there have been relatively few PADs created, it is difficult to determine what factors predict clinicians’ real-life propensities to override PADs. However, in response to a hypothetical vignette, 47 percent 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).

Research has also examined completed PADs for adherence to community standards of care (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 percent and 83 percent of the time, respectively (Swanson, Swartz, Elbogen, et al., 2006). In other research, 16 of 17 factors were rated as consistent with community standards of care 96 percent 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 percent of the time (Srebnik & Russo, 2007). In both of these studies, which reviewed over 340 completed PADs, no document refused all treatment. Although 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, 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, 2d Cir. 2003]).

PAD Outcomes

To this point, the reviewed evidence indicates that PADs are valued by various mental health stakeholder groups, albeit for somewhat different reasons; still, the uptake of PADs remains minimal because 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 have shown 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 et al., 2007; Swanson, Swartz, Elbogen, et al., 2006). Other research indicates that PADs were able to reduce the use of coercive crisis interventions (for example, 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 documentation being legally binding on the mental health provider (Henderson et al., 2008), found that the use of coercive interventions was significantly reduced over time. In addition, there were fewer instances of violence for those with JCPs than those without (Henderson et al., 2004). Another study in the United Kingdom, 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, JamnMohamed, Davidson, & Dawson, 2002). In another study, Srebnik and Russo (2008) 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 percent of crisis events. This same study noted that there were low rates of consultation with proxy decision makers during crises; when proxies were “involved,” though, the PAD was significantly more likely to be accessed (Srebnik & Russo, 2008). Although in toto these findings show promise, this latter finding regarding the lack of
involvement of proxies is concerning, because their involvement is seen as important for successful PAD implementation (Backlar, 1997). Finally, qualitative research has attempted to describe, from the consumer's perspective, some of the strengths and limitations of PADS as actually experienced during mental health crises (Kim et al., 2007). This research found that most participants expressed enthusiasm regarding the implementation of PADS but also concern regarding clinicians' general lack of awareness of PADS. In addition, some consumers were uncomfortable even mentioning to clinicians that they had a PAD for fear of a negative response or some type of involuntary treatment during their hospitalization.

CRITIQUE OF PRIOR RESEARCH ON PADS

Though initial studies are promising, there are several areas where research remains lacking. First, little research has followed consumers for extended periods of time to assess the long-term effects of PADS (the outcome studies reviewed earlier 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. If PADS are to be effective, the service system must support their creation, access, and use. However, PAD outcome studies have traditionally lacked this contextual focus. Little research exists on effective ways to overcome barriers to access and use of PADS, including comparing ways to ensure that PADS can be accessed at any time (for example, living will registries, medical-alert bracelets, state registries, PADS filed with likely inpatient destinations). Empirically tested interventions are needed to educate and improve provider attitudes regarding PADS so that they may support PAD creation and use. 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 use could be promising but have yet to be rigorously explored.

Third, prior PAD research lacks the consumer's voice. It is ironic that, although 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 a client's declarations and (2) they are predicated on direct involvement of the client's primary clinician in helping create the document—lead to better outcomes for some clients than for others (for example, people with SMI who are distrusting of legal documents)?

Fifth, there has been little research into the stability of preferences, errors in HCPA decisions, and cognitive biases in predicting satisfaction with future treatment choices. All of these affective forecasting issues are relevant to PADS and should be explored, including whether errors in affective forecasting lead to disappointment with PADS and, if so, with what consequence.

Sixth, and finally, little research has explored PADS in the context of race and culture (Van Dorn, Swanson, & Swartz, 2009). There has been little effort to disaggregate racial and ethnic groups beyond traditional white/nonwhite designations in consideration of desire for or actual uptake of PADS. In addition, 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, groups that have 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 people 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 medicolegal 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 nonmajority groups or cultures? How might membership in multiple oppressed groups (for example, SMI and gay/lesbian, SMI and racial minority) affect the impact of PADS?
As discussed earlier, research is lacking in ways to overcome barriers to PAD use. 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/antioppression 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 in which PADs can be implemented.

In addition to research, studies suggest that social workers are in need of education regarding PADs. 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 NASW (1996) Code of Ethics. In addition, 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 to prepare a PAD. Education regarding 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 a 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 in which 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 (for example, the DVD Crisis and Control: What's the Role of Psychiatric Advance Directives [for more information, see http://www.unlistedfilm.com/crisis.html] could be used in classroom, practicum, or clinical settings), and discuss PAD use 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 in 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 at Duke University Medical Center (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.

Original manuscript received October 1, 2008
Final revision received June 3, 2009
Accepted June 15, 2009

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