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Understanding the Personal and Clinical Utility of Psychiatric Advance Directives: A Qualitative Perspective

Mimi M. Kim, Richard A. Van Dorn, Anna M. Scheyett, Eric E. Elbogen, Jeffrey W. Swanson, Marvin S. Swartz, and Laura A. McDaniel

Psychiatric advance directives (PADs) are legal tools that allow competent individuals to declare preferences for future mental health treatment when they may not be capable of doing so as a result of a psychiatric crisis. PADs allow individuals to maintain self-determination during times when they are most vulnerable to loss of autonomy and in need of assistance to make their preferences known and honored. This article describes the content of twenty-eight open-ended, semi-structured qualitative interviews of adults with PADs who have experienced psychiatric crises. The qualitative analysis revealed three major themes from the interviews: (1) PADs as tools for empowerment and self-determination, (2) limited knowledge of PADs among service providers; and (3) difficulties communicating PADs to inpatient staff. In general, many participants expressed enthusiasm of the implementation of PADs but concern regarding clinicians’ general lack of awareness about them. Additionally, some consumers discussed discomfort in even mentioning that they had a PAD to clinicians for fear of a negative response from them, or some type of involuntary treatment during their hospitalization. However, participants consistently viewed PADs as a positive tool to promote autonomy with the potential to facilitate stronger patient–provider relationships. Therefore, when working with individuals in psychiatric crisis who have a PAD, and who have never before experienced a sense of control over their own treatment, clinicians must recognize the potential troubling disequilibrium this sense of control may engender. In sum, though the most significant challenges facing the implementation of PADs involve clinicians’ familiarity with and education about PADs, much promise for the future growth of PADs lies in the benefits perceived by the patients.

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This work was supported by the MacArthur Foundation and a National Research Service Award Postdoctoral Traineeship from the NIMH to Drs. Kim and Van Dorn and NIMH K02 to Dr. Swanson.

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It felt like, I don’t know, I was just really scared. Sometimes I have a hard time remembering things or telling people things what I want and certain stuff and it felt like I was all alone inside there.

–Adult study participant describing a recent hospitalization

Individuals with severe mental illnesses (SMI) often describe a sense of confusion, fear, and inability to communicate their treatment wishes and have them respected during a crisis. Psychiatric advance directives (PADs) are one potential mechanism available to persons with SMI to help minimize many of the ambiguities commonly associated with mental health crises. PADs are legal documents that allow competent individuals, through advance instructions (AI) and/or designation of a Health Care Agent (HCA), to declare preferences for future mental health treatment when they may not be capable of doing so as a result of a psychiatric crisis (Appelbaum, 2004; Joshi, 2003; Swartz, Swanson, & Elbogen, 2004). This study uses qualitative interviews with adults with SMI who had completed a PAD and had a subsequent mental health crisis to examine consumer views on and experiences with PADs and mental health services.

BACKGROUND

A growing body of literature posits manifold benefits of PADs for individuals with SMI. Specifically, it has been proposed that PADs have the potential to increase autonomy, decrease the need for coercive interventions, and improve clinical outcomes through an increase in provision of preferred services during crises, improved engagement in the treatment process, and an enhanced sense of self-efficacy, connection, and empowerment (Backlar & McFarland, 1998; Howe, 2000; Srebnik & LaFond, 1999; Swanson et al., 2000; Widdershoven & Berghmans, 2001). However, the literature also notes a number of potential barriers to PAD implementation and effectiveness. These include low rates of PAD creation by consumers (Swanson, J.W., Swartz, M.S., Ferron, J., Elbogen, E.B., Van Dorn, 2006), operational features of the mental health service system (e.g., lack of communication between staff, lack of access to the document), or clinical barriers (e.g., inappropriate treatment requests, such as refusal of necessary medications; consumers’ desire to change their mind about treatment during crises) (Van Dorn et al., 2006).

In addition, PADs shift authority from the provider to a relationship based more on shared decision-making. In the absence of clinical alliance, some providers may be reticent to inform individuals with SMI about PADs, work with them in creating PADs, or invoke the PAD during crises. A number of studies report varying levels of clinician support for PADs. These estimates range from a low of 20% to over 80% of clinicians indicating their support for PADs (Amering et al., 1999; Atkinson, Garner, & Gilmore, 2004; Backlar et al., 2001; Elbogen et al., 2006; Srebnik 2004). Given the novelty of PADs, such varying rates of PADs endorsement, particularly the lower rates, are not surprising. One study found that eight to ten months after creating a PAD, 46% of persons with SMI expressed concern or dissatisfaction with it, primarily as a result of providers’ lack of education about PADs and lack of willingness to honor them (Backlar et al., 2001). Elbogen and colleagues (in press) examined the opinions of 591 clinicians (psychiatrists, psychologists, and social workers) to assess their attitudes and decision-making in relation to PADs. They found that approximately 51% of the clinicians were unsure of the impact of PADs.

Given the fairly recent introduction of PADs to both consumers and providers, multiple questions remain, including the consumers’ reasons for completing PADs, their views on the utility of PADs, and the most efficient process for communicating not only that one has a PAD, but also its contents during times of crisis. For example, what role, if any, does direct, personal experience with involuntary treatment play in consumers’ decisions to
complete a PAD? Can consumers demonstrate appropriate insight regarding the risks and benefits of completing a PAD? This issue is especially important because the participants’ understanding of PADs will shape their expectations of what the PAD can offer them. Without a clear understanding, consumers may become disenchanted or disappointed by PADs, threatening the long-term utility of PADs in their treatment. Related questions arise when considering PADs in the context of crisis events. For example, are PADs reviewed and honored by clinicians during crises? If so, how does honoring the PAD impact the consumer? Conversely, what are the effects on consumers’ overall treatment outcomes when the PAD is not honored during a crisis?

This study seeks to address these questions through the examination of qualitative interviews of persons with SMI who completed a PAD with the assistance of a facilitator and had a subsequent crisis during which they were either hospitalized or felt they should have been hospitalized. The paper explores and reports on these individuals’ experiences with the mental health system before, during, and after the crisis, the impact of the PAD on their crisis and mental health care, and their general views regarding the utility of PADs. We then discuss the implications of the findings as they relate to consumers’ support of PADs; the pattern of provider interactions with PADs, particularly during crisis situations; and the overall utility of PADs in mental health treatment.

METHOD

These data were collected as part of a larger, longitudinal, randomized control trial (RCT) that examines the effects of a facilitated Psychiatric Advance Directive (F-PAD) intervention on three sets of outcomes: (1) PAD completion, structure, and content; (2) outpatient treatment engagement; and (3) crisis management. The primary target population for PADs is a subset of adults with SMI who experience psychotic symptoms associated with fluctuating decisional capacity and who are at risk for involuntary treatment. Accordingly, the study’s sample criteria were as follows: (1) age 18–65; (2) chart diagnosis of schizophrenia, schizoaffective disorder, other psychotic disorder, or major mood disorder with psychotic features; and (3) currently receiving community-based treatment provided through one of two county-based programs in the state mental health system of North Carolina, located in the north-central region of the state; (4) able to give informed consent to the study, which entails the ability to participate in a research interview in English and provide informative answers to basic questions about personal background, previous mental health treatment, and preferences for and against given forms of treatment. At the conclusion of the RCT baseline interview, each participant received random assignment to the F-PAD intervention or control group.

A sample of 469 patients with SMI were randomly assigned to the F-PAD session or a control group receiving written information about PADs and a referral for assistance from existing resources in the public mental health system. Prior to giving informed consent, the research staff member explained the benefits of being in each group. Specifically, if assigned to the F-PAD group, a research staff member would help the participant complete a PAD. If assigned to the control group, the research staff would provide the participant with information on how to complete the PAD. Also, control group participants would be given extra help completing a PAD once the study participation was completed. If the participant wished to receive help before the study ended, he/she was offered an opportunity to attend a group meeting about PADs and the phone number of a consumer organization that could assist them with the completion of the PAD. Sixty-one percent of F-PAD participants completed legal advance instructions and/or authorized a proxy decisionmaker; 3 percent of control group participants completed these legal instruments.

Since the questions explored in this study concern consumers’ subjective experiences and views on PADs, a qualitative methodology was chosen. A qualitative approach
explores individual experiences and “alternative ways of knowing” by using dialogue and emergent themes that delve beneath the surface of aggregate data (Guba, 1990). Qualitative methodologies are particularly relevant when the issues under investigation are relatively new and questions have yet to be clearly and completely explicated (Amering, Stastny, & Hopper, 2005), as is the case with the current state of PADs.

An open-ended and exploratory set of questions was developed by the authors to explore concepts related to consumer insight, awareness of risks and benefits of PADs, treatment preferences, patient-provider interactions around treatment preferences, and perceived benefits of PADs. Throughout the data collection process, data were continually examined for the purposes of modifying the wording of future interview questions to better focus on the emergent themes in greater depth. This initial stage of analysis followed a grounded theory approach. This approach follows a traditionally qualitative recursive and iterative process where the earlier interviews are referenced in order to inform and shape future inquiries (Burck, 2005). This approach is appropriate for discovery-oriented research and is most often used in under-theorized areas of research (Burck, 2005; Glaser & Strauss, 1967; Henwood & Pidgeon, 1996).

Twenty-eight open-ended interviews were conducted by three members of the research team who were experienced with qualitative research as well as the larger RCT. Participants were recruited from the larger RCT after they reported a recent mental health crisis and agreed to take part in this qualitative project. The definition of crisis included both hospitalization and feeling the need to be hospitalized. The inclusion of the latter group was based on the belief that PADs may help certain people avoid hospitalization. The sample of participants included 16 females and 12 males. Of the 28 participants, 64 percent \( n = 18 \) were African American and 36 percent \( n = 10 \) were Caucasian. The median age of the 28 participants was 42 years and the median reported age of onset for mental health and substance abuse problems was 22 years of age.

The qualitative research staff contacted each participant by phone after they provided initial consent to the RCT interviewer. During this follow-up interaction on the phone, the qualitative interviewer explained the purpose of the interview and also confirmed that the participant had a PAD at the time of the reported mental health crisis. The interviewer also explained that the interview would last between 1 and 2 hours. Participants were then asked if they had any questions and whether they were still willing to take part in the study (only one individual refused to participate in the qualitative arm of the study). Once the participant agreed to complete a qualitative interview, he/she met with the interviewer in person to complete the taped, face-to-face interview. The interview began with another brief explanation of the objectives of the study, and then each participant provided written informed consent to take part in the tape-recorded interview. The interviewer explained that each interview would be transcribed without any identifying characteristics in order to preserve the anonymity of the participants; each participant was compensated $30 for their participation. All interviews were transcribed and then coded by one member of the research team using Atlas.ti, version 4.1.

RESULTS

Analysis revealed three major themes from the interviews: 1) PADs as tools for empowerment and self-determination, 2) limited knowledge of PADs among service providers; and 3) difficulties communicating PADs to inpatient staff.

PADs as Tools for Empowerment and Self-Determination

Throughout the qualitative interviews, multiple themes related to PAD benefits emerged. An important and recurrent theme was the use of PADs as a way to maintain con-
control during a time of vulnerability. This control could be maintained through the advance instruction (AI) function of the PAD by identifying specific hospitals to go to if hospitalized and providing the primary clinician with a copy of the PAD to refer to during crisis events. As one participant explained:

Having a PAD makes me feel a little more secure because like I said, if anything ever happened to me, then I know that I’m not going to go to just any hospital and be treated by anybody. The doctors will hopefully have a copy of it. That’s why I want a copy to give my doctors at [name of hospital] so that in case something happens to me, they know how to treat me if I come into the hospital.

Another participant remarked on the benefit of specifying treatment refusals and requests:

Yes, I want control even if I’m not in control. You know? Control issues are always an issue for me when an emergency occurs and if I need to be admitted to a hospital and give up controls, then I still want people to know what’s best for me.

For other participants, the benefit of a PAD was in identifying a legally recognized proxy decision-maker, a Health Care Agent (HCA). One participant described the potential benefits of her HCA with the following:

Say I need meds and it could be meds that I don’t want, according to my PAD. So the person that I gave [healthcare power of attorney – HCPA] to could go to my doctor and say, well, she really needs this Haldol. If she does not get this Haldol then, you know, boom! The HCPA gives my HCPA the power to say “go ahead.” See, [when I’m like this], anything I say will be ignored because by me being sick, they think that I am not in my right mind so giving her the power of attorney allows her to take the next step.

In such an instance, the participant gains the security of someone acting on their behalf during a crisis situation; however, the potential risk is the consumer’s disappointment if the HCPA makes a request that is not clinically feasible at the time of crisis.

Consumers also indicated that PADs were a tool to command respect from providers during crises. One participant stated that a specific stipulation of his PAD was that he “be treated with respect and to have them listen to me.” A participant whose PAD had been read and attended to during a crisis reported the following:

The doctor didn’t treat me like a nut case because some hospitals do. You know what the doctor said to me? [He said] “You’ve got rights and it’s great that you know you have them.” That’s what he said. He said to me, “Now you know your rights and we’ll try to respect those completely.”

Interestingly, even though many of the participants that were interviewed reported frustrations with not having their PADs acknowledged or honored, many of them still expressed positive sentiments similar to the following (from a participant who reported that his PAD was not acknowledged by the hospital staff):

It’s probably one of the best things that’s come into mental health in a long time because it gives you rights, while you’re sound and while you know what’s best for you – and you’re the only person that knows what’s best for you deep down. You know what keeps you on track better than anybody. I would still recommend that at least people consider [the PAD] because it’s nothing but beneficial. You know it’s got nothing but good because people can have you committed and you don’t have a say about anything and that at least this way you do have some say in your treatment if it’s read and people see it and it’s legal – that’s another important thing about it.
Limited Knowledge of PADs among Service Providers

Many participants identified barriers to PAD implementation associated with providers’ lack of knowledge of or overall inertia to PADs. In many cases, participants indicated that clinicians were unaware of what a PAD was, were unwilling to believe that the consumer had a PAD, or did not recognize the PAD as an instrument to facilitate treatment. The following is one individual’s experience when he attempted to communicate with service providers regarding his PAD:

I showed the police the medical bracelet [part of the experimental procedure for the RCT] to tell them I had a PAD and they just saw my name but they didn’t call anybody. Then I showed the doctor at mental health and I told him that I had a PAD and he didn’t do nothing ... nobody told anybody at the hospital or nothing. I mean I told everybody that I had a living will registry [also part of the experimental procedure for the RCT] and they didn’t say nothing. I thought maybe the doctor at mental health would have known about it but he didn’t do anything. Then I had it [the bracelet] on my wrist the whole time I was at the hospital but then they told me that I had to take it off to be admitted; nobody even looked at it, but they were telling me I had to take it off.

Another participant describes a similar situation: “I told [my doctor] I had a PAD and showed it to him. He just looked at me and nodded sort of—that was it. He didn’t ask me anything, didn’t tell me he was going to call them [the living will registry to obtain a copy of the document] or anything...” A participant aptly described his frustrations when the hospital didn’t ask him about his PAD: “The PAD is supposed to be there for me when I need it and I just couldn’t believe that [the doctors] didn’t know anything about it... For the kind of money they charge you, you ought to have some kind of rights.” When asked how his hospital stay might have been different had the staff been aware of his PAD, he said, “I think that they would have at least recognized the fact that I had some rights to say what medications I wanted to be on, what they were doing to me...”

Perhaps the most ubiquitous theme emerging from these data was the need for hospital staff to become more familiar with and accepting of PADs. This is evidenced by the following exchange between a consumer and interviewer:

Interviewer: “... but do you think they’ll help you at all in the future?”
Consumer: “Maybe when more people start using them.”

Interviewer: “Talk a little bit about that—how would that help?”
Consumer: “Well a lot of people don’t even know what it is, like the staff at the hospital.”

One participant conveyed his attempt to overcome some of the barriers and potential risks associated with not having one’s PAD available by making sure that all of the relevant stakeholders in his treatment were aware of and had a copy of it:

And the reason I gave so many people a copy of it was if there needs to be a time when it needs to be used, I don’t want any confusion from anybody about what needs to be done. ... If one person isn’t available, then another person should be and if that person’s not available, then someone else should be. Everybody I’ve showed it to, including my therapist, thinks it’s a great idea.

In some cases participants reported that even when the PAD was reviewed by providers no attempt was made to follow the specified requests. One participant reported the following:

When I got up to [mental health center] I told them I had one [a PAD] and they said—their excuse was, “We can’t always honor this because there may not be beds at this particular
hospital, or so on and so on.” It was just a complete run around. They weren’t treating me with any respect.

Certainly, the practicality of specific treatment requests cannot always be followed. As a result, in the main RCT, if a consumer was in the F–PAD group, research staff explained the limitations that might interfere with the implementation of certain aspects of the PADs, such as bed availability. Research staff emphasized that PAD treatment requests should be perceived as preferences, but not necessarily requirements.

**Difficulties Communicating PADs to Inpatient Staff**

A number of participants stated that they often did not volunteer information about their PAD when in crisis. When asked if she had told anyone about her PAD when taken to the hospital, one participant replied, “No, I didn’t tell anyone until the mental health doctor came in. I didn’t think of telling anyone until I saw him.” Another participant commented on how difficult it was to remember the PAD once in crisis by saying the following:

I don’t know, it’s still kind of hard to picture using or even remembering that I have an advance directive if I have to go to the hospital because when I’m that bad, sometimes I can’t even remember my own name, much less to let the hospital know that I’ve got this, what is it again, oh yeah, psychiatric advance directive.

Other participants appeared to be so concerned about the potential for involuntary treatment that it affected the way they interacted with hospital staff, particularly regarding communicating about the PAD. When asked if he told hospital staff he had a PAD, one participant reported the following:

No, I didn’t say nothing to those people cause they was like—they wasn’t really listening to nothing that I had to say, they weren’t really paying me no attention, it was like I wasn’t really there, I was just there to be admitted and I didn’t have no say—so about nothing that I showed anyone. I didn’t want to end up with them putting me in seclusion or something so I just went along with whatever they said. So I didn’t want to get in no trouble.

Though such behavior from clinical staff seems to be less frequent than non-responsiveness to PADs because of unfamiliarity, PADs are a particularly valuable tool for consumers like this who have experienced demoralizing staff during crisis situations. Another participant made a similar statement when asked if she would feel comfortable notifying staff of her PAD:

It probably depends on the situation, you know. I think if I feel like I’m in a hostile situation, I might not consider it. But if I’m in a situation where I feel like there is respect and concern for my situation, then I would probably be much more certain about doing it.

For some participants, having a PAD was a way to avoid or reduce future involuntary treatment in the hospital. A participant expressed this by saying, “It means that I will have some say—so . . . That I’ll have some input into what goes on in my treatment, and in my medication. That’s something I’ve never had before.”

In the current study, 65 percent of the sample reported having experienced physical involuntary treatment (such as restraint and seclusion, or handcuffing) in the hospital (n = 17). One participant described a sense of powerlessness during a recent hospitalization with the following:

It was like I was just a patient there—they didn’t want to have anything to do with me besides me just being a patient there as far as carrying on a conversation or seeing how I was on a day-to-day basis. None of that really seemed important to them. They were just concerned with doing their job and that
was it. I was just a patient to them. I had to
do what I was told. Move when I was told to
move and go to bed when I was told to go to
bed. It was just like that—really like I was in
prison.

This corroborates past research showing
that PADs may be especially important for
those consumers who have experienced some
level of involuntary inpatient treatment in the
past (Srebnik & Brodoff, 2003; Swanson et
al., 2000).

Summary

These data provide an informative
glimpse into the experiences of persons with
SMI who reported having a mental health cri-
sis after completing a PAD. Some of the expe-
riences were positive and beneficial while oth-
ers were clearly disheartening and frustrating
to those involved. Still, as evidenced by the fol-
lowing narrative, when clinicians are aware of
and have access to the PAD, and when the
stated preferences are respected by clinicians,
the beneficial aspects of PADs are apparent:

I pretty much carry my PAD around every-
where. I told the police about my PAD be-
cause they were the first people I spoke to
when I got taken to the hospital last time.
Then, when the ambulance took me to [name
of hospital], it was really crowded in the ER
so I showed intake my PAD and told them
that I needed to go somewhere quiet with less
people so that I could calm down because I
can’t be around a lot of people at once. The
intake nurse sat with me in a quiet room until
I calmed down.

DISCUSSION

Qualitative analyses revealed that
many participants expressed enthusiasm
about having a PAD but concern regarding
clinicians’ general lack of awareness of about
them. Additionally, some consumers dis-
cussed discomfort in even mentioning that
they had a PAD for fear of a negative response
from their clinician, or some type of involun-
tary treatment during their hospitalization.
However, participants consistently viewed
PADs as a positive tool to promote autonomy
with the potential to facilitate stronger
patient–provider relationships.

A number of implications related to
both clinical practice and future research can
be drawn from these findings. First, some par-
ticipants experienced reticence regarding their
PAD and its potential to contribute to future
involuntary treatment during a mental health
crisis. Specifically, a number of participants
expressed concern about informing hospital
staff of their PAD for fear of not being paid at-
tention to, or even worse, incurring some type
of punishment (e.g., being put in seclusion or
restraints) for mentioning the PAD. Other
participants communicated the potential for
clinicians to intimidate them during a
psychiatric crisis, thus deterring them from
introducing their PAD.

At the same time, while some partici-
pants did express these fears, several partici-
pants reported feeling “fortunate” to have a
“say–so” in their treatment, indicating that
this was something that they had “never had
before.” Therefore, when working with indi-
viduals in psychiatric crises who have a PAD,
and who have never before experienced a
sense of control over their own treatment, cli-
nicians must recognize the potential disequi-
librium this sense of control may engender.
Coupled with a history of involuntary treat-
ment, this disequilibrium is likely to exacer-
brate discomfort with or intimidation by
hospital staff.

As a result, it appears important for cli-
nicians to provide a safe environment to initi-
tate discussions with consumers regarding
PADs. This sense of needed safety and respect
for the PAD was clearly expressed by one par-
ticipant when she was asked to reflect on what
would help people in crisis feel more comfort-
able discussing their PAD with a clinician:

People with mental problems need [PADs] but
it’s not good if the doctor or whoever you
show the PAD to in the hospital can just crum-
ble it up and throw it aside. It has to be read and they have to have some respect for it.

While this sample appeared to have good insight into their illnesses and treatment needs, there were still instances where the concept of the PAD presented problems for some consumers. Specifically, some participants reported problems remembering that they had a PAD during a psychiatric crisis. However, the majority of those interviewed indicated that the PAD offered a sense of security during the crisis. Specifically, they perceived the PAD as an opportunity to inform staff of their own psychiatric history, typical behaviors during crises, and treatment preferences.

The main implication of this appears to be that mental health service systems, particularly hospitals, ought to create an operational structure that trains and allows staff to not only inquire about PADS, but also to implement patients’ treatment requests (Van Dorn et al., 2006). Findings from these data, in addition to prior research (Backlar et al., 2001; Srebnik & Brodoff, 2003; Srebnik et al., 2005) indicate that clinicians’ concerns that PADS will be used to refuse all treatment have largely been unfounded. Instead, it appears that PADS are likely to be feasible, useful, and in agreement with community standards of care.

These qualitative data present perspectives of consumers able to identify both benefits and barriers associated with PADS. Specifically, participants identified the benefit of having an HCA to enforce treatment choices identified in the PAD, particularly prescriptive PADS where the consumer will stipulate an imposed restraint or restriction in their treatment. This was relevant for consumers who either indicated adverse reactions to certain medications used in the past and thus proscriptively declined their future use, or those who had responded well to certain treatments and thus prescriptively requested their continued use.

Furthermore, some participants discussed the sense of security that the PAD provided. For example, through the PAD, they have a chance to express preferences for certain hospitals where providers are aware of their needs. However, some of the challenges that participants associated with PADS included: not informing the provider of the PAD (for multiple reasons as discussed above); clinicians not knowing what a PAD is; and clinicians not adhering to certain treatment preferences included in the PAD. One participant described her doctor as feeling “overwhelmed” by her PAD, both because he was unfamiliar with the concept of PADS and because of the copious amount of information in her PAD. These potential risks and benefits of PADS should be explored and examined in greater detail to determine what length and content is most effective for consumer and clinician use.

These interviews also demonstrate that providers’ exposure to PADS varies significantly. For instance, some participants described situations in which clinicians ignored their claims of having a PAD. Others described scenarios where clinicians acknowledged the consumer having a PAD but did not react to any treatment requests or comment on the nature of the preferences. It has also been found that clinicians may also consider legal liability as a significant concern when dealing with PADS and specified treatment preferences (Van Dorn et al., 2006). But in fact, because it is a fairly rare event for a consumer to be hospitalized and bring up having a PAD, measuring how often clinicians are unaware of or ignore treatment requests specified in a PAD becomes quite a challenge.

The same current state laws that authorize PADS also give providers discretion to ignore them (Swanson et al., 2006–a; Swanson et al., 2006–b). Specifically, in cases where the consumer’s advance choice of treatment conflicts with the provider’s view of the standard of care, PAD laws do not require that the provider follow the patient’s wishes. In fact, most of these laws provide broad legal immunity to providers who, in good faith and consistent with clinical standards, decline to follow a consumer’s PAD (Swanson et al., in press–a; Swanson et al., in press–b). Overall, clinicians are obligated to follow whatever portions of the PAD they can, even if they override some
particular instructions. However, granting clinicians the discretion to decide which PAD instructions are to be followed, and which are not, weakens the instrument to some degree. Weakening PADs even further, civil commitment law trumps a PAD in every U.S. jurisdiction.

Despite these challenges, many participants reported both the current and future value of PADs, not only when clinicians become more aware of the laws and documents, but also more familiar with how to effectively implement them. Perhaps most importantly, the sample conveyed positive sentiments regarding the sense of security and rights PADs afford people with mental illness. In some cases, participants were able to describe the positive impact PADs had on their treatment when clinicians followed their PAD.

Given the small sample size and grounded theory approach inherent in this qualitative study, limitations regarding the generalizability of these findings should be considered. Many themes emerged, some more positive than others. Some of the obvious and consistent themes include the extent to which clinicians were unaware of PADs and the potential benefit PADs present individuals with severe mental illness, particularly those with extensive mental health services and psychiatric crisis experiences. As with any qualitative study built on the foundations of grounded theory, these interviews and emergent themes provide a stepping stone from which further study can build.

In sum, though the most significant challenges facing the implementation of PADs involve clinicians’ familiarity and education about PADs, much promise for the growth of PADs lies in the benefits perceived by consumers. The complexity of assimilating PADs into mental health treatment involves not only consumers, clinicians, and other key stakeholders, but also requires significant changes in the infrastructure of the mental health service systems to integrate a legal tool that strives to strengthen the consumer–provider alliance in treatment delivery. This task is not to be underestimated, especially when clinicians and the larger service system may face the potential for inappropriate treatment preferences and legal liability. But as PADs gain wider acceptance among individuals with SMI, clinicians, policy makers, and the overall mental health system, future research findings should replicate the benefits that have been found in this study and increase the promise of the application of PADs as a frequently used treatment tool.

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