Abstract Objective Psychiatric advance directives (PADs) allow individuals to plan for future mental health treatment. However, little is known about barriers to PAD completion. This paper examines an intervention’s effect in reducing barriers to PAD completion. Method Patients were randomly assigned to a facilitated PAD session or control group. Barriers associated with (1) the PAD documents and (2) external support for PADs were assessed at baseline ($n = 462$), 6 months ($n = 380$) and 1 year ($n = 362$). Results There were no significant baseline between-group differences on the two barriers. However, at follow-up both barriers were significantly lower in the experimental group. Further, barriers were predictive of PAD completion. Conclusions Structured facilitation can significantly reduce barriers to PAD completion. However, the intervention did not eliminate barriers. Findings are discussed in the context of possible system-level changes to further reduce barriers to PAD completion.

Keywords Psychiatric advance directives · Barriers · Mental illness · Intervention

Recent research has begun to describe the applied benefits associated with completing psychiatric advance directives (PADs). This research has moved beyond demonstrating a large latent demand for PADs (Swanson et al. 2006b) to indicating that interventions designed to facilitate completion of PADs can improve treatment satisfaction, working alliance and competence to make treatment decisions (Elbogen et al. 2007; Swanson et al. 2006a). Evidence also indicates that completed PADs evince strong clinical utility, including appropriate and useful references to available services and treatments (Srebnik et al. 2005). However, research suggests that while a majority of consumers with severe mental illness would desire PADs, a very small proportion has actually completed them (Swanson et al. 2006b). A recent randomized trial demonstrated that a structured facilitation can dramatically increase PAD completion rates (Swanson et al. 2006a). Results from this study indicated that 61% of participants in the facilitated session completed an advance directive or authorized a proxy decision maker, compared with only 3% of control group participants. The current paper builds on these core findings and attempts to answer questions related to (1) specific types of barriers preventing PAD completion, (2) whether perceived barriers predict PAD completion and if so, (3) how to effectively reduce these barriers. Broadly, the question remains: if structured facilitation enables people with severe mental illness to complete PADs, how does it work and, how can facilitations be improved to allow more persons with mental illness to successfully complete PADs? The current study examined a structured intervention’s effect in reducing specific barriers to the completion of PADs over the course of 1 year.
Background on Psychiatric Advance Directives

Psychiatric advance directives are legal documents that allow patients to consent to or refuse future mental health treatment in the event of an incapacitating psychiatric crisis through the documentation of advance instructions and/or appointment of a surrogate decision maker (Srebnik and La Fond 1999). Demand for and interest in PADs have resulted in legislation in 25 states wherein PADs have either been authorized in new statutes or by revisions to existing health care decision laws. The initiation of a MacArthur Foundation-funded national resource center on psychiatric advance directives (see http://www.nrc-pad.org) is further evidence of increasing interest in PADs. Despite this recent legislative action, many questions remain unanswered regarding certain aspects of PADs, including the need and ability to reduce perceived barriers to completion, particularly factors associated with the PAD documents themselves and external support for PADs.

Barriers and Psychiatric Advance Directives

The discrepancy between consumers’ demand for PADs and their actual completion of these legal documents may be due to the varied and substantial barriers to PADs facing both consumers of mental health services and the systems that treat them (Swanson et al. 2006a; Van Dorn et al. 2006b). On the one hand, 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’ inappropriate treatment requests and desires to change their mind about treatment during crises (Van Dorn et al. 2006b). It is possible that these barriers have prevented clinicians from fully supporting consumers’ completion of PADs. On the other hand, consumers report barriers related to difficulty in understanding PADs, skepticism about their benefit and lack of contact with a trusted individual who could serve as proxy decision maker, or simply not having a clinician to trust (Swanson et al. 2003).

Conceptual Framework

This study assesses change in consumers’ perceived barriers to PAD completion in a 1-year randomized trial of an intervention to facilitate PAD completion by persons with severe mental illness. (For information on the parent study, see Swanson et al. 2006a). This study addresses the following four questions: (1) Are perceived barriers related to PAD documents themselves and external support for PADs reduced over time for the experimental group compared to the control group? (2) What characteristics of consumers are associated with reduced barriers? (3) What is the PAD completion rate for those whose barriers were reduced over time compared to those whose barriers increased over time? (4) Do perceived barriers predict PAD completion? These questions are grounded in a conceptual framework that includes relevant demographic, clinical and social factors that draw on prior research findings regarding demand for (Srebnik et al. 2003; Swanson et al. 2006b), completion of, and outcomes associated with PADs (Elbogen et al. 2007; Srebnik et al. 2004; Swanson et al. 2006a).

Study Design

A total of 469 patients with severe mental illness were randomly assigned to a facilitated psychiatric advance directive session or a control group that received written information about psychiatric advance directives and referral to resources in the public mental health system. Perceived barriers to PAD completion were assessed at baseline, 1, 6 and 12 months.

Sample Selection

The study’s sample criteria included: (1) age 18–65; (2) chart diagnosis of schizophrenia, major mood disorder with psychotic features, or bipolar disorder; (3) currently receiving community-based treatment provided through one of two county-based programs in the north-central region of North Carolina; and (4) able to give informed consent to the study.

The Facilitated Psychiatric Advance Directive (F-PAD) Intervention

The F-PAD is a semi-structured, manualized interview and guided discussion of choices involved in anticipatory mental health treatment planning. The F-PAD is adapted from several medical and psychiatric advance directive planning tools (California Protection and Advocacy, Inc. 2003; Colvin and Hames 1991; Hammes and Rooney 1998) while incorporating the required statutory elements of PADs specific to the state of North Carolina.

The intervention was conducted by five trained research assistants, one with a master’s degree and the others with bachelor’s degrees. They were trained to fidelity by a doctoral-level clinical psychologist until they consistently achieved a score of at least 87% on 15 fidelity criteria. Reliability and fidelity were then monitored by random observation and fidelity measurement, with remediation as needed.
The intervention included orientation to PAD concepts, review of past treatment experiences, and documentation of future treatment preferences. If the participant wished to prepare the relevant legal PAD documents, the facilitator provided assistance with completing these forms. The specific sections of the advance instruction and health care power of attorney statutory forms (e.g., including medication choices, facilities preferences, powers granted to, or withheld from, the health care agent) are used to organize and guide discussion of the participant's preferences. The facilitator also assisted the participant in obtaining witnesses, notarization, and filing forms in the medical record and an electronic registry. The intervention also allowed the facilitator to contact, with participants' consent, potential HCAs to explain the process and answer any questions they had about what to do during a crisis.

Control Group

Participants in the control group were given an introduction to PADS, written materials describing the purpose of PADS, copies of standard PADS forms, and the toll-free telephone number of the local consumer organization that provides consultation to persons who wish to prepare PADS. Participants with poor literacy skills had the materials read to them aloud. However, control group participants were not assisted with contacting the local consumer organization nor were they given aid in filling out PAD forms.

Screening, Informed Consent, Recruitment and Randomization

A random sample was drawn from de-identified lists of mental health program clients pre-screened for eligibility. Sequential admissions from the programs to the regional state psychiatric hospital were also screened. Following informed consent and baseline interview, each participant was randomized to the F-PAD intervention or control group. As soon as possible following the baseline interview, a separate session to conduct the F-PAD was scheduled with participants who were randomized to the experimental group. The study protocol was approved by the Duke University Medical Center Institutional Review Board (IRB) and by the IRBs of the participating programs and hospital.

Measures

PAD Barriers

Participants were asked to rate their perceptions of barriers to the completion of PADS. The four barriers assessed were: (1) not understanding the document(s); (2) not knowing what to say or write in the document(s); (3) having no one trustworthy to make decisions or naming someone for the HCA; (4) having no clinician to trust or an inability to get information from one's clinician about what to include in the PAD.

Identification of these PAD barriers is based on our prior work, including feedback from prior stakeholder surveys that examined factors associated with PADS (cf., Swanson et al. 2003). Our intent in specifying these four barriers was to tap into two potential conceptualizations of barriers faced by consumers, specifically “barriers associated with the PAD documents themselves” (i.e., not understanding the document and not knowing what to say or write in the document) and “barriers associated with external support for PADS” (i.e., having no one trustworthy to make decisions and not having a clinician to trust). This conceptualization of barriers is theoretically consistent with our prior research on clinicians' perceptions of barriers to PAD implementation (Van Dorn et al. 2006b) where clinicians identified barriers related to the PAD documents and systemic barriers external to the PAD documents. For the current analyses, barriers ranged between zero and two for each of the two barriers and were assessed at baseline, 1, 6 and 12 months.

Covariates

Five time-variant covariates, which were assessed at the three study time points, were included in all multivariable models. Working alliance was assessed with the short form of the Working Alliance Inventory (WAI) adapted for use with SMI individuals (Horvath and Greenberg 1989; Neale and Rosenheck 1989). Satisfaction with mental health services was measured by utilizing several items from the Mental Health Statistics Improvement Program (MHSIP) Consumer Survey Index of Treatment Satisfaction (Ganju 1999). Some participants who were interviewed could not answer the questions regarding mental health services or working alliance with a clinician, because they had not received services recently enough, and did not have enough contact with a clinician, to be able to rate these items. In these cases, items with missing values on the two measures were imputed as neutral scores (Swanson et al. 2006a). The number of monthly outpatient mental health visits was also included in multivariable models, with those having more than one visit compared to those with one or zero visits. The anchored version of the Brief Psychiatric Rating Scale (BPRS) was used to assess current psychiatric symptoms (Woerner et al. 1988). Finally, a single item was used to assess perceived social support. This item read, “In times of trouble, can you count on at least some of your family or friends?” Respondents indicating that this was true for
them “most of the time” were compared to respondents indicating that they could count on family or friends “hardly ever/never” or only “some of the time” (Van Dorn et al. 2006a). Time-invariant covariates assessing race (whites were compared to non-whites), sex (males were compared to females) and diagnosis (bipolar disorder and major depressive disorder with psychotic features were compared to schizophrenia) were also included in all multivariable models.

Analysis

For research questions one and two, barriers to PAD completion over a 1-year period (baseline, 6 months and 12 months) were estimated with a Poisson model for repeated measures with SAS v.9.1 (Diggle et al. 1994; Stokes et al. 1995). These models incorporate all available longitudinal data for each participant, and estimate the net association of multiple fixed as well as time-varying predictors of reduced PAD barriers. The models also adjust for lack of independence between observations for each participant over time by using an autoregressive covariance structure, i.e., a matrix wherein the correlation gradually declines between baseline and successive follow-up measures of the dependent variable (PAD barriers). For research question three, a chi-square analysis was used to assess differences in changes between baseline and 6 month barriers and rates of PAD completion. Finally, for research question four, a logistic regression was used to assess whether or not perceived barriers at 6 months predicted completion of PADs for those assigned to the experimental condition, controlling for baseline barriers.

Results

Sample Characteristics

At baseline, the average age of participants was 43 years (standard deviation = 10.7 years). The sample was 60% female, 40% white and only 12% were married or cohabiting. Twenty-six percent of the sample had less than a high school education and only 24% of participants worked for pay in the past month while 59% of participants were living independently at baseline.

Regarding clinical characteristics, 57% of participants had a chart diagnosis of schizophrenia or related psychotic disorder, 28% had bipolar disorder and 16% had depression with psychotic features. The mean score on the Brief Psychiatric Rating Scale (BPRS) was 33.0, with a standard deviation of 9.1, indicating a moderate level of symptomatology. Finally, 35.3% of participants reported more than one outpatient visit during the past month.

Research Questions One and Two

Bivariate Differences in PAD Barriers

At baseline there were no significant differences between the experimental and control conditions on either of the two types of barriers (see Table 1). Both groups reported the most substantial barriers to be those associated with the PAD documents themselves. Approximately three-quarters of the participants in both groups reported barriers related to the PAD documents whereas one-third of participants in both groups stated that they perceived barriers associated with external support for PADs. Throughout the course of the study, however, the experimental group progressively reported fewer barriers than did the control group.

F-PAD Effects on Barriers

Tables 2 (barriers associated with the PAD documents themselves) and 3 (barriers associated with external support for PADs) display the results of the F-PAD intervention’s effect on reducing barriers to PAD completion. Each of the multivariable tables contains three models. The first model shows results from the comparison between the experimental and control conditions while the second model adds relevant covariates, including time and sociodemographic, clinical and social support characteristics. The final model in each of the tables adds the effect for the experimental-condition-by-time interaction.

The first multivariable regression models in Tables 2 and 3 indicate significant differences between the experimental and control conditions for both types of barriers: those associated with the PAD documents (OR = 0.83, \( P < 0.01 \)) and those associated with external support for PADs (OR = 0.73, \( P < 0.01 \)) over the 1-year study period.

Controlling for time and sociodemographic, clinical and social covariates did not change the outcomes between the experimental and control conditions. In these second models, there was a significant and negative main effect for time when assessing barriers related to the PAD documents. (The effect of time for the barriers related to external support for PADs was not significant.)

With regard to diagnoses, those with bipolar disorder were less likely to report barriers related to the PAD documents than were those with schizophrenia. Those with depression with psychotic features, however, were more likely than those with schizophrenia to report these barriers. Considering other clinical variables, there was significant and positive main effect for psychotic symptoms as measured by the BPRS; this significant and positive effect was found for both types of barriers. Additionally, there were significant and negative main
effects for treatment satisfaction (barriers associated with the PAD documents) and working alliance (for both barriers associated with the PAD documents and barriers associated with external support for PADs). Finally, social support was a significant and negative predictor of reporting barriers related to external support for PADs.

The third model for Tables 2 and 3 includes the effect for the experimental-condition-by-time interaction. In these models, the experimental-condition-by-time interaction indicated that those receiving the intervention were significantly less likely to report either of the two types of barriers over the 1-year study period than were those assigned to the control group. Effects for the significant covariates from model two remained unchanged when models included the intervention-by-time interaction.

Research Questions Three and Four

**PAD Barriers and PAD Completion**

Briefly, results from the core outcome paper examining the effects of the PAD-facilitation showed that 61% (n = 146) of participants in the experimental condition completed a PAD; this was in comparison to only 3% (n = 7) of those in the control condition that completed a PAD (Swanson et al. 2006a). While those prior results demonstrated that the facilitation increased rates of PAD completion, the current results indicate that the intervention was able to significantly reduce barriers over time for those in the experimental group compared to those in the control group. However, the question remains as to whether or not these barriers were indeed related to PAD completion. In order to address this issue we conducted two additional analyses. The first analysis examined the PAD completion rate for those whose barriers were reduced over time compared to those whose barriers increased over time. The second analysis examined the ability of the barriers to predict PAD completion; both of these analyses were conducted on those assigned to the experimental condition. (The ability to conduct a similar analysis on the control condition was not possible given the low rate of PAD completion in this group.)

For the former analysis two groups were created: (1) those whose barriers started and remained at zero between baseline and 6 months in addition to those whose barriers decreased between baseline and 6 months (e.g., started at 2 and went to 1 or 0; or started at 1 and went to 0) and (2) those whose barriers started and remained at either 1 or 2 between baseline and 6 months in addition to those whose barriers increased between baseline and 6 months (e.g., started at 0 and went to 1 or 2; or started at 1 and went to 2). Differences in rates of PAD completion were then examined between these two groups for both types of barriers (i.e., those related to PAD documents and external support for PADs).
to the PAD documents and those related to external support for PADs). Fifty three percent \( (n = 100) \) and 68.8\% \( (n = 130) \) of participants had their barriers remain at zero, or decrease, between baseline and 6 months for the barriers related to the PAD documents and external support for PADs, respectively. This was in comparison to 47.1\%
treatment decisions within PADs (Elbogen et al. 2007)."

"... barriers related to the PAD documents and external support for PADs, respectively."

"When assessing barriers related to the PAD documents, those whose barriers remained at zero or decreased between baseline and 6 months were significantly more likely to complete a PAD than those whose barriers remained at one or two, or increased between baseline and 6 months (73.0% compared to 56.2%; P < 0.05). When assessing barriers related to external support for PADs, those whose barriers remained at zero or decreased between baseline and 6 months were significantly more likely to complete a PAD than those whose barriers remained at one or two, or increased between baseline and 6 months (70.8% compared to 52.5%; P < 0.05).

"We next conducted a multivariable logistic regression examining the relationship between one’s 6 month barriers and PAD completion while controlling for one’s baseline barriers. This analysis indicated that both types of barriers had a negative effect on PAD completion. Specifically, those reporting barriers related to the PAD documents were 41% less likely to have completed a PAD (OR = 0.59, P < 0.05) while those reporting barriers related to external support for PADs were 44% less likely to have completed a PAD (OR = 0.56, P < 0.05).

Discussion

This study examined (1) the ability of a facilitated intervention (F-PAD) to reduce perceived barriers to PAD completion and (2) the relationship between these barriers and PAD completion. Findings from the current study complement and expand upon earlier findings indicating that a facilitated intervention increased the rate of PAD completion for persons with severe mental illness randomly assigned to an experimental condition compared to those assigned to a control condition. Specifically, 61% of participants in the facilitated session completed an advance directive or authorized a proxy decision maker, compared with only 3% of control group participants (Swanson et al. 2006a).

The present study yielded three findings of note. First, the intervention reduced individual barriers related to PAD documents—i.e., not understanding the PAD and not knowing what to write in the PAD. This result augments previous evidence from the same study showing that the F-PAD intervention significantly improved the competence of cognitively-impaired clients to write PADs and make treatment decisions within PADs (Elbogen et al. 2007). Second, the intervention reduced barriers related to external support for PADs—i.e., not having anyone to trust or fulfill the roles of a health care agent (HCA) and problems with one’s primary clinician. Third, reduction of these specific types of barriers appears to have functioned as an important mechanism by which the intervention actually resulted in completed PADs. These findings reinforce the effectiveness of the F-PAD intervention by providing insight into how it works.

The intervention may also have had some effects beyond mere completion of a PAD. By assisting the individual in selecting a person to serve as HCA, and addressing concerns about the clinician, the F-PAD session may have positively affected participants’ perceptions of individuals around them. It is noteworthy that the intervention exerted a significant effect on these external support variables, even controlling for the covariate effects of therapeutic alliance and social support. Those completing PADs may have done something more than simply fill out the requisite paperwork; at least some of them may have had helpful conversations with family, friends and clinicians about their past, current and desired forms of treatment. Indeed, data from a separate, qualitative component of the study lends some support for this explanation (Kim et al. 2007).

However, the F-PAD intervention did not completely eliminate barriers to PAD completion, and some people completed PADs despite persistent barriers. Some scholars have voiced concerns that consumers may complete PADs without appropriate reflection and discussion (Amering et al. 2005). The current data suggest that people can complete PADs without clearly understanding what these documents are for and how they work. It seems likely that such PADs would be less often invoked and less effective in guiding treatment. In future research it will be important to assess whether or not different models of PAD facilitation, including a process that involves one’s treatment team directly (e.g., akin to joint crisis plans; cf., Henderson et al. 2004; Henderson et al. 2008), can more effectively reduce barriers over time and also lead to beneficial implementation of PADs in practice.

The study has a potentially broader message about the importance of ongoing social and therapeutic support for persons with severe mental illness. Specifically, social support in the current research was a significant and negative predictor of barriers associated with external support for PADs. Social support has also been shown to moderate the relationship between perceived barriers to care and mandated treatment (Van Dorn et al. 2006a). Therefore, better, or more positive, relationships with friends and family, as evidenced by the PAD consumer-HCA agreement, might allow patients to avoid mandate-related barriers to treatment. Consequently, by reducing these barriers, PADs may also reduce the need for “leveraged” community treatment (i.e., treatment mandates related to housing, representative payees, criminal justice or..."
outpatient commitment; cf., Monahan et al. 2005; Swanson et al. 2000). Additionally, if relationships with clinicians or other formal service providers are improved, then long-term improvements in psychiatric status and service utilization are more likely (Facciniani et al. 1990; Shaw et al. 2000). Further investigation should address these potentially beneficial “secondary” outcomes related to PAD facilitation, and examine how the perception of social support affects not only barriers to PAD completion but also treatment engagement and personal autonomy.

Finally, these findings provide a starting point for the discussion of tailoring PAD facilitations for persons with particular clinical characteristics, including different diagnoses. The current results indicate that persons diagnosed with bipolar disorder were less likely to report barriers associated with the PAD documents than were those with schizophrenia. However, those with a diagnosis of depression with psychotic features were more likely than those with schizophrenia to report these same barriers; these findings held when controlling for psychotic symptoms. Given that research into PADS and PAD facilitations is still developing it will be important to confirm or disconfirm these findings in future research, in addition to better explicating reasons for these potential differences.

Consistent with the current findings, other recent research has indicated that those with a psychotic diagnosis showed lower performance when being evaluated for competence to make treatment decisions within PADS compared to those with other disorders (Elbogen et al. 2007). It is possible that psychiatric disorders impede one’s understanding of PAD documents, in addition to what content to include in the documents. However, it appears that a PAD facilitation can dampen some of these barriers. Still, a more nuanced understanding of these issues is important if PAD interventions are to develop a stronger evidence-base; thus ensuring that people with severe mental illness, regardless of diagnosis, achieve a desired outcome with respect to PADS.

The main limitation of this study is that the benefits of the PAD facilitation may not generalize to all persons with severe mental illness. Patients who were not engaged in treatment or who refused consent to participate may have had different responses to the facilitation, or may have articulated a more intractable set of barriers to PAD completion. Also, we were unable to examine outcomes associated with non-F-PAD completed documents (i.e., those completed by persons in the control group) as there were too few of these types of documents completed in the randomized trial. However, future research will want to assess whether or not the positive outcomes identified in this paper generalize to consumer-completed documents.

In sum, we find evidence that a structured, facilitated intervention can effectively reduce multiple barriers to PAD completion—barriers related to both the PAD documents (i.e., understanding and knowing what to write) and external support for PADS (i.e., having someone to trust for the HCA function of PADS and improving relations with one’s primary clinician). Further, we find that barriers to PAD completion affect the likelihood of people completing PADS. The current research adds to a growing coda of studies that are beginning to find both short- and long-term benefits of PADS, and of PAD facilitation. In particular, these findings indicate that to a large extent, the facilitated intervention (Swanson et al. 2006b) worked by reducing these barriers to PAD completion. However, significant system-level change is required before PADS achieve their potential and become an accepted part of mental health treatment (Srebnik and Brodoff 2003; Van Dorn et al. 2006b).

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