

Psychiatric Advance Directives: A Survey of Persons With Schizophrenia, Family Members, and Treatment Providers

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Psychiatric advance directives (PADs) allow competent persons to request or refuse specific types of treatment and designate a proxy decisionmaker in advance of a mental health crisis when they may lose capacity to make reliable healthcare decisions. A survey of attitudes and opinions about PADs was conducted in three stakeholder groups with a sample of 104 persons with schizophrenia and related disorders, 83 family members of persons with severe mental illness (SMI), and 85 clinicians who treat persons with severe mental illness. Among the sample of persons treated for schizophrenia, only 7 (6.80%) reported having a PAD, but 62 (67.39%) reported that they would complete a PAD if provided assistance. Respondents in all three stakeholder groups largely expressed great interest in PADs, but indicated that they had little or no experience with these new legal instruments. Patients, family members, and clinicians differed substantially in their opinions about the goals of PADs, the likely effectiveness of these instruments, and who should be legally bound by them. Respondents with schizophrenia perceived significant barriers to completing a PAD. Stakeholders have interest in, and high hopes for PADs; however, significant barriers prevent successful implementation of PADs as intended. It may be necessary to provide resources to assist persons with SMI in completing PADs, configure information systems to make PADs accessible, and educate clinicians about the potential benefits and drawbacks of PADs and their legal obligations regarding PAD compliance.

Psychiatric advance directives (PADs) are relatively new legal instruments that may be used to document a competent person's specific instructions or preferences regarding future mental health treatment, in preparation for the possibility that the person may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness (Appelbaum, 1991; Winick, 1996). All states permit some form of legal advance directive (AD) for healthcare, which can be used in conjunction with at least some forms of psychiatric treatment. Typically, these instruments authorize a surrogate decisionmaker with Durable Power of Attorney for Healthcare to act in accordance with an incapacitated patient's previously-expressed wishes, known values, or to act in the patient's best interest if the patient's preferences are unknown.

ADs generally were designed to control decisions about end-of-life healthcare, e.g., to limit life-sustaining medical interventions that fail to provide a meaningful quality of life for terminally-ill patients. However, these legal instruments have significant limitations when applied in the context of mental health treatment for incapacitated psychiatric patients. Some states' laws do not permit proxy decisionmakers to authorize certain types of mental health intervention (e.g., psychiatric hospitalization when the patient cannot give informed consent). And whereas some psychiatric patients might wish to pre-authorize treatment using an AD that is irrevocable during a crisis (i.e., when their decisional capacity may be impaired), most states allow medical patients to revoke their ADs even while incapacitated if they are able to

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communicate a choice to do so. Given these and other perceived limitations, fifteen states in the past decade have adopted specific PAD statutes tailored for psychiatric patients who may experience fluctuating capacity to make treatment decisions. These instruments allow psychiatric patients to document in advance, while competent, their acceptance or refusal of particular types of mental health treatment and intervention. Some of these laws also incorporate authorization of proxy decisionmakers specifically for mental health treatment. In all of the new PAD statutes, revocation of a PAD is conditioned on competency to make healthcare decisions; PADs remain legally in effect during periods of decisional incapacity (Fleischner, 1998).

Despite increasing interest in PADs and the promulgation of laws authorizing PADs, very little research has been conducted with representative samples to answer emerging policy questions: What is the level of support for PADs among persons with serious mental illness, their family members, and clinicians? How do stakeholder groups differ in their perceptions regarding PADs' underlying rationale, purposes, likely effectiveness, and the barriers to completing and implementing PADs? Are PADs seen as a potential alternative to involuntary treatment? Do stakeholders differ in their opinions about whether PAD instructions should be legally binding on clinicians and mental health facilities, and irrevocable during a mental health crisis? This paper addresses these questions with the results of a descriptive and comparative survey of experiences, attitudes, and perceptions relevant to PADs in three stakeholder groups: (1) persons treated for schizophrenia or schizoaffective disorder, (2) family members of persons with severe mental illness (SMI), and (3) mental health clinicians who provide treatment for adults with SMI.

Background. Over the past decade, two significant developments on the legal landscape surrounding patients' rights have generated increasing interest in PADs. First, the Patient Self-Determination Act (PSDA) of 1991 introduced a new set of federal requirements intended to implement advance directive policies at all healthcare facilities that receive federal funding through Medicaid and Medicare programs (Greco et al., 1991). Mental health-legal scholars and consumer advocates recognized that the PSDA had implications for

psychiatric treatment, and also saw a potential opportunity in the PSDA to promote the empowerment of patient choice in mental health services (Hoge, 1994; Kapp, 1994)—notwithstanding concerns and evidence that medical advance directives are often ignored or ineffective (Howe, 2000; Teno et al., 1997; Wolf, 1991).

The PSDA requirements apply equally to psychiatric facilities and general hospitals, and include several key elements regarding advance directives. Specifically, healthcare facilities are obligated to: 1) inform patients of their rights under state law to make decisions concerning their own health care, including the right to accept or refuse treatment and the right to formulate advance directives; 2) document in the patient's current medical record whether or not the patient has an advance directive; 3) formulate policies for implementing patients' rights including the right to prepare advance directives, and inform patients in writing of these specific implementation policies; 4) ensure compliance with state law respecting advance directives; and 5) Provide education for staff and the community on issues concerning advance directives (United States Code, 2000).

The original intent of the PSDA was to ensure that patients know they have a right to prepare an advance directive to retain control over their future medical treatment if a time should come when they are unable to communicate their wishes directly. Patients are free to exercise that right or not, but advance directives do not abrogate hospitals' obligation to treat patients according to appropriate standards of care and practice; at the same time, hospitals cannot use their obligation to treat patients appropriately as an excuse to override a patient's advance directive.

Potential conflicts may arise between healthcare providers' perceived legal and ethical duties to provide the specific treatment that they believe is best for patients, and their obligation to abide by patients' own wishes regarding acceptance of recommended treatment. Such conflict may become especially problematic in the case of individuals who suffer from severe psychiatric disorders, which may, at times, significantly impair judgment and the ability to recognize the gravity of one's condition and need for intervention (Halpern & Szmukler, 1997; Sales, 1993). Whether advance directives for mental health

treatment will prove to be a help or a hindrance in resolving such conflicts is a matter of current debate, supported by opinions but sparse empirical evidence on either side. Preliminary studies of opinions about PADs suggest that these instruments are promising, but much more definitive research is needed (Amering et al., 1999; Backlar et al., 2001).

The second motivating force behind the rise of PADs in recent years has been the intense reaction in some quarters against policies of legally mandating psychiatric treatment (Lefley, 1993)—particularly outpatient commitment policies (Swartz & Swanson, 2002; Swanson et al., 2000). Outpatient commitment has been criticized as offering a perverse choice between coercion and neglect. In contrast, PADs appear to offer a more positive alternative: the possibility of both patient empowerment and beneficial treatment. Might the deleterious pattern of fragmented, intermittent, and often involuntary treatment be changed by advance planning on the part of persons with mental illness themselves? In theory, a PAD—and the process of preparing a PAD while competent—could facilitate engagement in the treatment process, help to mobilize clinical resources as necessary, improve adherence with beneficial therapies, facilitate communication between providers, caregivers and patients, and thus help to avert psychiatric crises or improve management of such crises without resort to involuntary commitment (Amering et al., 1999; Backlar & McFarland, 1996; Brock, 1998; Savulescu & Dickensen, 1998; Srebnik & La Fond, 1999; Stavis, 1999). Hoping for these benefits, 16 state legislatures to date have adopted specific PAD statutes—providing a legal means for persons with SMI to give advance instructions for their treatment during a future mental health crisis, and/or to appoint a proxy decisionmaker to carry out their wishes for treatment should they become incapacitated.

What do stakeholders think of PADs? Answering this question is an important first step in addressing larger issues concerning whether PADs will provide any benefit—and if so, how and to whom. Over the past several years, there has been growing recognition of the need to take into account perceptions and opinions of consumers, family members, and treatment providers when examining and evaluating the broad impact of mental health policy, both intended and unintended effects. Investigators have

elicited stakeholders' opinions about mental health laws (Davidson et al., 1996), changes in mental health systems (Pulice, McCormick, & Dewees, 1995), mental health service needs (Grella & Grusky, 1989; Grusky, Tierney, & Spanish, 1989; Hayward, Peck & Smith, 1993), patient advocacy movements (Evans & McGahah, 1998; Geller, Brown & Fisher, 1998), mental health housing services (Nelson, Hall, & Walsh-Bowers, 1998a; Nelson, Hall & Walsh-Bowers, 1998b), health priorities and outcomes (Hoof, Weeghel, & Kroon, 2000; Lee et al., 2000; Rosenheck, 1999) and health care reform (Fisher, 1994). Notably, there has been a shift toward incorporating consumers' and family members' opinions to better inform policy making (U.S. Department of Health and Human Services [DHHS], 1999). Ultimately, the goal of examining stakeholders' opinions is to generate a knowledge base about how members of key groups agree and disagree on significant policy issues, so that efforts can be made to foster stakeholder cooperation, dialogue, and communication to improve mental health services (Barriera et al., 2000; Corrigan et al., 1999). This paper addresses a gap in knowledge, along these lines, regarding stakeholders' opinions and attitudes about PADs.

METHOD

Sample

We collected data about views of PADs from three stakeholder groups in North Carolina: (1) persons in treatment for schizophrenia and related disorders, (2) family members, and (3) clinicians. The sampling method and sample characteristics are described in what follows:

Sample of persons with schizophrenia and related illnesses. The participants in this group were adults with schizophrenia and related disorders who had recently completed an observational study of mental health treatment under "usual care" conditions. Eligible participants included persons who had received treatment for a recently-documented DSM-IV diagnoses of schizophrenia, schizoaffective disorder, or schizophreniform disorder, who were age 18 years or older, and resided within a defined area of north-central North Carolina. Participants also had

to be able to provide written informed consent to participate in the research project.

Despite giving informed consent, a small number of participants demonstrated difficulty comprehending the interview. In those cases, the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975) was administered; if the subject committed three or more errors on this instrument, the interview was stopped and data not used. In addition, interviewers rated the respondents' level of comprehension of the interview; data for those rated as not understanding the interview were excluded. Eleven participants were excluded from the study on these criteria. There were 104 participants with schizophrenia and related disorders in the final sample. Table 1 displays the sample frequency distribution by sex, race, age, and educational attainment.

Family Sample. Two subsamples of family members were recruited totaling 83 respondents. Forty-nine family members (59%) were recruited initially by asking the participants in the group with schizophrenia for permission to contact a family member. Respondents with schizophrenia who gave informed consent to contact a family member provided one to three family contacts, ranked by the closeness of the patient's relationship with those

family members. The family member with the closest relationship to the patient was approached first. Only one family member per consumer was recruited for the study. To increase diversity in the family sample, we recruited 34 (41%) additional family members through advertisements placed in a local daily newspaper and in the newsletters of area chapters of the National Alliance for the Mentally Ill (NAMI). Family participants who worked as mental health clinicians in the past two years were excluded, as were family participants who reported being hospitalized for mental health problems in the past five years ($n = 2$). The same comprehension standards were used for family members as for patients. Only one family member was excluded for this reason.

The two groups of family members did not differ in gender or age, but they differed in racial background: 73.5% of the patient-recruited group were African-Americans, while only 38.2% of those recruited through advertisements and the NAMI newsletter were African Americans, $\chi^2(1, 83) = 10.30, p < .005$. The two subgroups also differed on years of education: those recruited through patient contact had an average of 11.8 years of education, while the other group had an average of 15.6 years of education, $t(81) = -6.39, p < .0001$.

Table 1
Sample Description

	Persons With Schizophrenia and Related Disorders	Family Members	Clinicians
N	104	83	85
Percent Male	54.81	25.30	40.00
Percent African-American	73.08	59.04	23.53
Mean Age (Standard Deviation)	43.94 (9.26)	54.38 (15.78)	44.46 (9.48)
Mean Years of Education (Standard Deviation)	11.55 (2.25)	13.39 (3.28)	
			% with M.D. 51.76

Clinician Sample. The clinician sample ($n = 85$) was selected from the staff rosters of area community mental health centers, psychiatric units of general hospitals, and local private-practice psychiatrists in the region who were identified as primary mental health service providers for persons with schizophrenia and related disorders. Self-administered questionnaires were sent to 100 clinicians whose disciplines included psychiatry, psychology, clinical social work, and case management for adults with serious mental illness. When a survey instrument was returned due to an invalid address or because the clinician no longer worked in the area ($n = 8$), the next clinician on the roster in the same discipline was sent a survey. Fifty-three of the instruments were sent to psychiatrists, 10 to clinical social workers in inpatient settings, and 37 to clinical social workers and case managers in outpatient settings. Clinicians who did not return the questionnaire were sent three reminders. This method yielded a response rate of 85%. The clinicians had an average of 12.85 years experience ($SD = 8.82$ years) in the mental health field (excluding time spent in training). Twenty-seven were employed at a state hospital, 37 at a community mental health center, 10 at a health center, 11 at a veterans affairs medical center, 19 at a medical school, 16 in private practice, 5 in a correctional facility, and 5 in other settings. Some clinicians were employed in more than one setting. The educational credentials of the sample of clinicians included 44 M.D.s, 1 Ph.D., 1 Psy.D., 25 MSWs or other master's degrees, 3 R.N.s, 9 bachelor-level graduates, and 2 case workers with less than a B.A. degree. A majority of clinicians ($n = 51$, 60%) reported that 25% or more of their caseload consisted of patients with schizophrenia, while only 18 (21.2%) reported less than 10% of their caseload consisted of patients with schizophrenia.

Procedures

Trained field research interviewers fully described the study, obtained written informed consent, and conducted interviews with participants from the patient and family subsamples. The interviewers were trained to repeat questions as often as needed and to use neutral probes if answers were inconsistent or seemed confused. Participants were

allowed to complete the interview in more than one session if desired and to take a break when needed. The interviews were conducted in the respondent's home, research offices, or other location agreeable to the respondent. The average length of an interview was 1.5 hours for the patient sample and 1.1 hours for the family sample. Respondents in these samples were compensated \$25 for their time. Clinicians' views were studied by a self-administered survey questionnaire distributed by mail. Clinicians' written informed consent to participate was obtained by their returning the completed questionnaire, which included an introduction that promised confidentiality and disclosed risks and benefits of study participation. Clinicians were paid \$50 for completing the survey.

Instruments

PADs were described to all participants as legal documents that may be used to "plan ahead to get mental health treatment in the future, in case you become too ill to decide what treatment you want or don't want." Patients were informed that a PAD (termed "Advance Instruction for Mental Health Treatment" in North Carolina) can contain instructions for future treatment with medication (both refusing and consent to certain medications) and advance consent to hospitalization in the case of illness relapse. They were also informed that a PAD allows persons to select a trusted individual to make future treatment decisions on their behalf if they should become incapacitated during a mental health crisis. Interviewers were trained to answer any questions about PADs before proceeding with the interview. Comparing a PAD to a "living will" was one commonly-used strategy for explaining PADs to those who were unfamiliar with the concept.

Participants with schizophrenia were asked if they had a PAD and, if not, if they would want to complete one if shown how. Family participants were asked if they had ever been given information about PADs. Clinicians were asked if they ever had a patient who had completed a PAD or someone with Health Care Power of Attorney for the purpose of advance planning for mental health treatment. They were also asked if they would recommend that a patient complete either of these documents if

someone was available to show them how. After a preliminary review of the results and debriefing of the interviewers, we learned that administrative and procedural difficulties in obtaining a PAD may be an important area of concern to patients. To capture this information systematically in the remaining interviews, questions were added to the patient instrument after the first nineteen interviews had been completed. All respondents with schizophrenia who did not report having a PAD were presented with a list of difficulties and barriers that might occur in trying to obtain a PAD, or might make them reluctant to obtain a PAD. For patients who reported interest in obtaining a PAD, this list was prefaced: "Please answer true or false to the following statements. You might have difficulty when trying to complete a PAD because..." For patients who reported no interest in obtaining a PAD, the same instructions were administered except that the preface read: "You don't want to create a PAD because..." Respondents with schizophrenia were also asked to give their own reason(s) for either not wanting a PAD or believing that they would have difficulty obtaining one.

We then presented participants in all three samples with ten statements about PADs and issues surrounding PADs. Participants rated these statements on a 5-point scale ("Strongly Agree," "Agree," "Neutral," "Disagree," or "Strongly Disagree"). These statements concerned attitudes toward PADs, proxy decisionmakers, reasons for completing a PAD, the revocability of PADs, and whether PADs should be legally binding on healthcare providers. All questions were part of a larger interview with an emphasis on views of, and experience with, coercion in treatment.

Data Analyses

Frequency distributions were calculated for all items, as were group differences across samples. For questions about the barriers to obtaining a PAD, those who said they would like a PAD and those who did not were compared using Fisher's exact test. Due to skewed distributions on these variables, and to clarify comparisons between groups, responses to the 5-point agreement scale were recoded into dichotomous variables, with "Strongly Agree" or "Agree" combined into one category and contrasted with all

other responses. Each sample was compared to the other two samples and differences were tested for statistical significance using Chi-Square tests. Significance tests were adjusted with a Bonferonni adjustment to correct for the increased likelihood of false positives caused by the three inter-group comparisons made for each question. Additionally, the two family subsamples were compared using Fisher's Exact Test to examine whether the two recruitment procedures produced subsamples that were different in their views on PADs.

RESULTS

PAD experience. Only 7 (6.8%) of the respondents with schizophrenia reported having a PAD, but most without a PAD said they would be interested in completing a PAD if they could be assisted in doing so (67.4%, $n = 62$). Few family members reported ever having received information about PADs (22.0%, $n = 18$) and there was no difference between the two family subsamples on that question. Only 10 clinicians (12.5%) reported having had a patient with a PAD or legally-authorized surrogate decisionmaker. However, among clinicians who expressed an opinion, almost all (95.8%, $n = 68$) reported that they would recommend that a patient complete a PAD or healthcare power of attorney if the patient were provided with assistance.

Difficulties and barriers. Table 2 shows the number of respondents who endorsed as "true" a series of statements describing difficulties and barriers likely to be encountered in obtaining a PAD, or reasons for not obtaining one. A majority of respondents identified the following as barriers to completing a PAD: lack of understanding of PADs, a belief that a PAD will not make any difference, and lack of knowledge about what to say in a PAD. Volunteered reasons for difficulties with PADs, or for lack of desire to obtain a PAD, were the following: (1) no need for a PAD because the patient did not perceive a need for mental health treatment ($n = 8$), (2) procedural difficulties in obtaining a PAD ($n = 5$), (3) objection to the concept of a PAD ($n = 4$), (4) the need for more information before making a decision ($n = 3$), and satisfaction with existing arrangements ($n = 1$).

Table 2

Difficulties in Obtaining PADs Reported by Respondents With Schizophrenia (n=78)

Question for those who did not want a PAD: Please answer true or false to the following statements. You don't want to create a psychiatric advance directive (or advance instruction) because:

Question for those who are interested in a PAD: Please answer true or false to the following statements. You might have difficulty when trying to complete a psychiatric advance directive (or advance instruction) because:

	True N (% of valid answers)	Difference Between Those Interested in a PAD vs. Those Not Interested
a. You don't understand enough about psychiatric advance directives (advance instructions)	61 (78.21)	<.05
b. It will take a lot of time and trouble	36 (46.15)	<.05
c. It will be hard to find someone or somewhere to get help to complete the psychiatric advance directive (advance instruction)	37 (47.44)	
d. You don't think anyone will pay attention to your wishes	29 (38.16)	
e. You don't think a psychiatric advance directive (advance instruction) will make any difference in your treatment	39 (50.00)	<.05
f. You don't know what to say in the psychiatric advance directive (advance instruction)	43 (55.84)	
g. You don't have anyone you trust enough to make decisions for you	30 (38.46)	
h. You don't have a doctor you trust	20 (25.97)	
Is there any other reason you (might have difficulties completing/don't want to create) a psychiatric advance directive?	21 (27.27)	<.05

Note: Group differences by Fisher's Exact Test, two tailed. Because of missing values, the N for these group difference tests is 75 (50 vs. 25).

Compared to those who said they would like to have a PAD (if someone assisted them in completing one), those who did not wish to have a PAD were less likely to indicate lack of understanding of PADs (64% vs. 87%; Fisher's Exact Test, $p < 0.05$), more likely to report that PADs would "take a lot of time and trouble," (64% vs. 36%; Fisher's Exact Test, $p < 0.05$), more likely to say that a PAD would not make any difference in their treatment (72% vs. 42%; Fisher's Exact Test, $p < 0.05$), and more likely to volunteer an additional reason for not wanting a PAD (44% vs. 14%; Fisher's Exact Test, $p < 0.05$).

Opinions about PADs. Table 3 shows the number of the participants in each sample who agreed or strongly agreed with each statement. There were no significant differences between the two family cohorts on agreement with these statements—with one exception: family members recruited through patient contact were more likely to agree that writing advance instructions probably will not do any good.

The vast majority of all three samples endorsed the idea that people with serious mental health problems should write down their treatment requests in case they become very ill in the future, and that they should talk to their doctor or therapist when doing so. Only a small minority of any sample agreed that writing advance instructions would probably not do any good. However, there was a difference of opinion between the samples in their assessment of the likely efficacy of an advance instruction to help people with mental health problems to stay well. While a majority of patients and family members agreed that advance instructions would help people with serious mental health problems stay well, clinicians were less likely to agree with this statement than either the patients, $\chi^2(1,184) = 23.26, p < .0005$, or family members, $\chi^2(1,164) = 6.28, p < .05$. Thus, patients had significantly higher expectations than clinicians regarding to the potential of PADs to actually improve patients' lives.

A majority of participants in all samples agreed that patients should appoint a surrogate to make treatment decisions in case of illness, but participants in the family sample were more likely than either patients, $\chi^2(1,185) = 10.27, p < .005$ or clinicians, $\chi^2(1,167) = 8.68, p < .01$, to support appointing a surrogate. This difference is consistent with the notion that the family members placed themselves in the role of surrogate decisionmaker, and therefore

were supportive of a mechanism that could give them more input.

Significant differences were found between groups regarding opinions on the revocability of PADs. Patients were significantly more likely than either family members, $\chi^2(1,183) = 17.84, p < .0005$, or clinicians, $\chi^2(1,185) = 6.93, p < .05$, to hold the view that an individual who has written advance instructions should be able to change his or her mind and revoke those instructions even when they are ill. However, the statement that PADs should be revocable in a mental health crisis did not achieve majority support in any sample, indicating that most respondents in all groups believed that the purpose of a PAD might be defeated if it were revocable by the patient during an acute episode of incapacitating illness.

All three groups differed from each other in their agreement with the statement that mental health providers should pay a legal penalty if they do not follow a patient's advance instructions. Patients were more likely to agree with this statement than were family members, $\chi^2(1,183) = 9.97, p < .005$, and much more likely than were clinicians, $\chi^2(1,185) = 49.92, p < .0005$. Though family members were less likely to agree with the statement than were patients, they were still significantly more likely to agree with it than were clinicians, $\chi^2(1,164) = 16.72, p < .0005$, i.e., to hold the view that clinicians should be legally penalized for failing to comply with a patient's PAD.

Reasons for supporting PAD. Though there were no significant differences between the samples in their endorsement of the statement that patients should write a PAD, there were between-sample differences in their support for the different reasons proposed for obtaining PADs. While a majority of all samples agreed that people with mental health problems should complete a PAD to gain more control over their lives in the future, clinicians were far less likely than patients, $\chi^2(1,186) = 44.73, p < .0005$, or family members, $\chi^2(1,167) = 31.91, p < .0005$, to agree that avoiding unwanted treatment is a good reason for writing a PAD. Additionally, when asked about obtaining a PAD to ensure that needed treatment is obtained, all three samples differed. Patients were more likely to support this statement than family members, $\chi^2(1,183) = 6.60, p < .05$, and clinicians, $\chi^2(1,185) = 28.66, p < .0005$. Though family members were less supportive of this statement than were patients, the family sample still

Table 3
Comparison Between Stakeholder Samples

	N (%) Reporting “Strongly Agree” or “Agree”					
	Respondents With Schizophrenia (Patients) N=104		Family N=83		Clinicians N=85	
	N (%)	N (%)	N (%)	N (%)	Between-Group Comparisons	
1. An advance instruction will help people with serious mental health problems stay well	80 (78.43)	52 (63.41)	36 (43.90)	<.0005	<.05	
2. People with serious mental health problems should, at some time when they are feeling well, write down what kind of medicine or other treatment they want in the future if they become very ill	82 (80.39)	67 (82.72)	73 (85.88)			
3. People with serious mental health problems should choose a family member or someone they trust and give that other person the right to make decisions about their treatment in the future if they become very ill	81 (78.64)	78 (95.12)	68 (80.00)	<.005	<.01	
4. Writing down advance instructions for mental health treatment will probably not do any good	13 (12.87)	11 (13.58)	6 (7.23)			
5. People with serious mental health problems should talk to their doctor or therapist about what to write down in an advance instruction for mental health treatment	89 (88.12)	70 (85.37)	74 (89.16)			

... continued

Table 3 (continued)
Comparison Between Stakeholder Samples

	N (%) Reporting “Strongly Agree” or “Agree”						Between-Group Comparisons		
	Respondents With Schizophrenia (Patients) N=104		Family N=83		Clinicians N=85		Patient-Family	Patient-Clinician	Family Clinician
	N	(%)	N	(%)	N	(%)			
6. Even if someone has written advance instructions for mental health treatment, they should always be allowed to change their mind—even when they are ill—about whether to go in the hospital and whether to take medicine	44	(43.56)	12	(14.63)	21	(25.00)	<.0005	<.05	<.0005
7. Doctors and hospitals should pay a legal penalty if they fail to follow a patient’s legal advance instruction for mental health treatment	63	(61.76)	31	(38.27)	9	(10.84)	<.0005	<.0005	<.0005
People with serious mental health problems should write down advance instructions for their treatment in a crisis, because									
8a. Otherwise they might be put in a hospital against their will or be given medicine that they do not want	78	(77.23)	59	(71.95)	24	(28.24)	<.0005	<.0005	<.0005
8b. Otherwise they might go without treatment that they need in order to get well	88	(87.13)	59	(71.95)	43	(51.19)	<.05	<.0005	<.05
8c. An advance instruction will give them more control over their own lives and what happens to them in the future	82	(81.19)	64	(79.01)	69	(81.18)			

Note: Percentages are given for valid answers. Missing values ranged from 0 to 3 per sample for each question. Significance tests by Chi-Square. Significance tests adjusted for multiple between-group comparisons using the Bonferroni method (Bland & Altman, 1995) with an adjustment of three.

showed more support for it than did the clinicians, $\chi^2(1,166) = 7.55, p < .05$.

Among the patients and family members, a majority of respondents endorsed the notion that PADs were a good idea for all three reasons—avoiding unwanted treatment, obtaining needed treatment, and empowering patient choice: 65.65% ($n = 64$) of patients and 54.32% ($n = 44$) of family members endorsed all three of the given rationales for PADs. In contrast, only 21.43% ($n = 18$) of clinicians supported PADs for all three reasons. Indeed, the greatest number of clinicians (32.14%, $n = 27$) endorsed PADs only for the purpose of making patients feel more empowered. Thus, it appears that many clinicians are somewhat skeptical about PADs as an efficacious mechanism for either treatment refusal or directing specific treatment options.

DISCUSSION

This study provides strong evidence that key stakeholders have a great interest in advance instructions and in appointing healthcare agents for mental health treatment. The vast majority of respondents in all three groups—patients, family members, and clinicians—endorsed the basic idea that people with mental illnesses should document the type of treatment they would wish to receive during a future mental health crisis. However, few respondents in any group had actual experience with these new legal instruments, and there were substantial differences between groups in opinions about what PADs are for, whether PADs are likely to accomplish certain goals, and who should be bound by them.

The survey identified sharp differences particularly between patients and clinicians. While the large majority of patients surveyed believed that an advance instruction would help people with SMI stay well, only a minority of clinicians held this optimistic view of the potential efficacy of PADs. Regarding the perceived purpose of PADs, nearly 8 out of 10 patients thought PADs should be completed as a means to avoid being involuntarily treated; in contrast, less than one third of clinicians endorsed that view. At the same time, however, patients were also much more likely than clinicians to view PADs

as a potentially efficacious means of obtaining the treatment they would want to receive in the future.

This survey also documented a common perception among patients that there are significant barriers that might prevent them from completing a PAD. Such barriers include: lack of understanding about PADs, inability to effectively express their treatment preferences, the belief that PAD instructions will not be accessible or followed, the belief that completing a PAD would be difficult and time-consuming, and that assistance with PADs is not available. Over a quarter of patients said they did not have a doctor they trusted—highlighting a potentially significant problem not only for PADs, but for treatment engagement generally among persons with schizophrenia and similar disorders.

The need to support and implement advance directives through the development of specific policies at healthcare facilities was recognized over a decade ago in the federal Patient Self-Determination Act (PSDA) (Greco et al., 1991). Since then, nearly one third of the states have enacted specific PAD statutes. The PSDA implicitly reinforces the authority of these statutes. Psychiatric facilities and mental healthcare professionals are not exempt from federal requirements to notify patients of their right to prepare advance directives; to make reasonable efforts to find out and to document whether incapacitated patients have advance directives or appointed healthcare agents; and—within the limits of standard practice and coinciding duties to care—to follow patients' advance instructions and preferences for treatment as documented. The National Mental Health Association has recently prioritized enforcement of mental health consumers' advance care documents in all 50 states. Still, little has been done actually to implement PADs.

Our survey results suggest there is a large unmet demand for PADs among consumers—and that clinicians and family members would support them—but that new policies are needed to address barriers to implementation of PADs. Such policies must address barriers at all levels of the PAD process, from orientation to PADs, to initiation, legal activation, revocation, compliance, and enforcement.

Our findings specifically highlight the need for consumer education and assistance with PADs; the majority of consumer respondents (77%) indicated that they did not understand enough about PADs to

complete a PAD document on their own. Along these lines, it may be necessary to put in place certain safeguards to ensure that completed PAD instructions are realistic and helpful, i.e., that PADs will ultimately provide some meaningful benefit to the persons whose wishes they document. Although PADs are designed ostensibly to promote consumers' autonomy in mental healthcare decisionmaking, PADs may be ineffective unless they also function as useful tools for clinicians and mental healthcare facilities—those ultimately responsible for complying with PADs but also for providing good care and appropriate treatment to those they serve. Policies to make PADs more useful might include routine orientation to PADs for consumers on intake to a mental healthcare facility; systematic evaluation of consumers' understanding of PADs and competency to complete a PAD; routine review of the PAD by a mental health professional; and consultation and assistance with PAD preparation through the services of a neutral facilitator.

Our research generally corroborates the results of another recent study that also queried mental health service providers about issues concerning PAD implementation (Srebnik & Brodoff, in press). That study reported on clinicians' concerns about a range of pragmatic issues such as accessibility of PAD information during a crisis, PAD enforceability, and PAD revocation. These findings likewise suggest the need for the development of clear implementation policies for PADs, as well as procedures to address potential problems that may arise around the use of these new legal instruments.

With respect to information access, centralized national registries and integrated computerized medical records hold promise for making PAD documents more readily available when needed. However, even assuming adequate access to PAD information in acute crisis situations, individual clinicians may or may not recognize PADs as valid legal documents. Alternatively, clinicians' concerns about their own legal liability and clinical autonomy may influence them to initiate involuntary civil commitment for patients with PADs who become incapacitated, i.e., simply to avoid being constrained by, and having to rely upon, these patients' advance requests for particular forms of treatment. Educational outreach and consultative support for clinicians

in implementing PADs may help address some of these issues.

Regarding the question of PAD revocability during a mental health crisis, our study found that consumers' and clinicians' opinions differed significantly. Clinician respondents generally were supportive of the provision in PAD statutes that requires competency to revoke a PAD. However, most consumer respondents held the opinion that PADs should always be revocable, even during a mental health crisis. This suggests there is potential for significant conflict between clinicians and some patients surrounding activation and implementation of PAD instructions, e.g., in cases when a patient has impaired decisional capacity and expresses a current wish to revoke a PAD or HCPA arrangement made in the past while competent. Practical policies have yet to be developed to provide clinical and legal guidance for adherence to PADs under such circumstances: how to prevent, resolve, or minimize potential conflicts around PADs, while avoiding involuntary commitment.

Clearly, if PADs are to be implemented widely and effectively in mental healthcare systems, these kinds of barriers and perceived difficulties must be addressed. Unless there are services provided to assist persons with SMI in completing workable PADs, unless information systems make PADs accessible, and unless clinicians are informed about their obligations with respect to PADs, it appears unlikely that PADs will live up to the high hopes that advocates have expressed.

This study is limited in some ways. The representativeness of the patient sample may not be optimal, since participants were selected after they had already been involved in a three-year observational study of schizophrenia treatment. Thus, patients who are not inclined to participate in research, are geographically mobile, and are already alienated from the mental health service system may be underrepresented in this sample. Nevertheless, the findings of this study, and the actions of sixteen state legislatures to date, suggest that PADs are a good idea at least in theory. No one really knows the true demand for PADs, whether or how they will be implemented, or exactly what services and information systems infrastructure will be necessary to support the implementation of PADs. The answers to those questions await the results of further research.

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