

How do Our Patients Respond to the Concept of Psychiatric Advance Directives? An Exploratory Study From India

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ABSTRACT

Background: Psychiatric advance directives have been incorporated in the Mental Health Care Act 2017 despite strong concerns about their feasibility and utility in the Indian patient population. Data on its utility in India is very scarce. **Aims:** To determine the possible treatment options our clients make as a part of psychiatric advance directives. **Materials and Methods:** Fifty consecutive individuals with severe mental illness were interviewed using a self-designed semi-structured tool to find out the possible choices they make as part of advance directives and the factors affecting their choices. **Results:** About 10% of the participants failed to understand the concept of advance directives. Of those who understood, 89% were willing to make advance directives, 15% refused future hospitalizations, 47% refused future electroconvulsive therapies (ECTs), and 62% refused physical restraints in future. **Conclusion:** The majority of the participants agreed to make advance directives. The majority of those who agreed to make advance directives refused to undergo ECTs and physical restraints in future episodes of illness. Approximately 10% of the patients could not understand the concept of advance directives.

Key words: Feasibility, Mental Health Care Act, psychiatric advance directives

INTRODUCTION


An “advance directive” (AD) is a legally binding document which describes the preferences for and refusals of treatment in advance.^[1] The concept of ADs is not new to psychiatry. Researchers have argued that ADs lead to improved medication adherence, reduced

escalation of symptoms in a crisis, better satisfaction with treatment, and accelerated recovery and enhanced dialog with healthcare professionals.^[2] However, a Cochrane review done to assess the usefulness of ADs and impact of ADs on the course of major psychiatric

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illnesses concluded that there is very limited scientific evidence favoring the ADs and urged for more research on the issue.^[3]

The Government of India ratified the United Nations Convention for Rights of Persons with Disability in September 2007.^[4] As a consequence, many measures have been taken to ensure the protection of the rights of persons with disability, one of them being the new Mental Health Care Act (MHCA) 2017 which will soon be enforced.^[5] Under MHCA, persons with severe mental illness will have the right to make ADs, to protect their rights to choose the treatment options in case of future exacerbation of illness.^[5] Many mental healthcare professionals across the country have expressed their concern about the feasibility of implementing the ADs in our country.^[6-8] Some have even suggested that the ADs should be kept out of the purview of the bill.^[8,9] Moreover, there are very few studies done to assess the feasibility and effectiveness of ADs in patients with major mental illness in India, and the need for more research is well recognized.^[7]

Till now, only three studies have assessed the feasibility and effectiveness of the AD in India. Shields *et al.* (2013) assessed the utility of ADs in India, focusing on the need for individual control over decision-making and the barriers to implementation. They interviewed 39 clients and 12 caregivers and concluded that introduction of ADs in India might be associated with positive outcome in some users.^[2] Pathare *et al.* (2015) tried to identify what service users would opt for if they make ADs. They included 75 individuals with major mental illness and found that most clients were comfortable with appointing a nominated representative and were willing to accept hospitalization and medications if needed. No client in their study refused the treatment outrightly.^[10] Gowda *et al.* (2018) assessed the factors affecting ADs. They found that 67% of the subjects welcomed the need for AD and that individuals with poor insight and active symptoms at discharge opted significantly more against ECT, antipsychotics, and hospitalization.^[11]

With this background of very limited research on psychiatric ADs from India, we took up this study to find out the possible treatment options our clients make as a part of ADs.

MATERIALS AND METHODS

Study setting and participants

It was a cross-sectional, descriptive, pilot clinical study conducted in the psychiatry department of a tertiary care general hospital. The psychiatric services in this hospital are provided free of cost or at a minimal expense. All consecutive individuals with a diagnosis

of schizophrenia or bipolar disorder (irrespective of subtypes) were screened for suitability for study enrollment. A purposive sampling was done. Individuals with age 18 years and above, who were adherent to treatment, were clinically asymptomatic for the past 3 months, and were willing to consent were included in the study. Individuals having major psychiatric comorbidities or mental retardation were excluded.

Treatment adherence was determined by both hospital records and the reports of reliable informant. Participants who have taken medicines as prescribed, for at least 80% of the days in the past 3 months, were considered to be adherent. Clinically asymptomatic state was determined using clinical records, information given by caregivers, and by CGI-S scale.^[12] The participants who, according to their clinical records and history by caregivers, were symptom-free for the past 3 months and also had CGI-S scores of less than 1 were considered asymptomatic.

Variables assessed

Variables assessed were attitude toward psychiatric ADs and possible choices the participants make while making hypothetical ADs. A specially designed questionnaire was used for the purpose. The questionnaire had four parts: The first part dealt with sociodemographic variables. The second and third parts dealt with clinical details and treatment details, respectively. The fourth part contained a set of questions designed to assess the attitude of patients toward advanced directives and the possible treatment choices they make in case of a future episode of illness. The preliminary draft of the questionnaire was prepared by two of the authors (B.T. and V.Y.P.), and it was later circulated among other authors for inputs. The revised draft was applied in five eligible patients before the study started, to understand the practical difficulties, and changes were made accordingly to arrive at the final draft.

Data collection and statistical analysis

All recruited individuals were explained about the concept of advanced directives (and that such provision will be made in future, once MHCA is enforced). They were asked to explain what they have understood about advanced directives, to ensure that their concept is clear. For those who had not understood, a maximum of three attempts were made to explain. The data were collected and tabulated. Fisher's exact test was used to assess the association between patient-related variables and the choices they make, with a *P* value of less than 0.05 considered to be significant. Bonferroni correction was used to avoid α error due to multiple analyses. Statistical analysis was done using Microsoft Excel 2017. Ethical clearance was obtained from institutional ethical committee.

RESULTS

Fifty consecutive individuals (30 patients with bipolar affective disorder and 20 patients with schizophrenia) were included in the study. The majority of the participants were young (60%), males (56%), educated up to secondary school (42%), married (58%), from middle-class strata (58%), and from a rural background (82%) [Table 1].

About 10% (5 of 50) of participants could not understand the concept even after the best efforts to make them understand. Of those who understood the concept, 89% (40 of 45) were willing to make an advanced directive. Of those who were willing to make advanced directives, 15% refused future hospitalizations, 22% refused chemical restraints (injectable psychotropics), 47% refused future electroconvulsive therapies (ECTs), and 62% refused physical restraints in future [Table 2].

Table 1: Sociodemographic details of the study participants

Variables	Subcategories	Values
Age	Young	30 (60%)
	Middle age	18 (36%)
	Elderly	02 (04%)
Sex	Males	28 (56%)
Marital status	Married	29 (58%)
	Single	20 (40%)
	Widow/widower	01 (02%)
Occupation	Skilled	09 (18%)
	Semi-skilled	22 (44%)
	Unskilled	19 (38%)
Educational status	Uneducated	02 (04%)
	Primary	18 (36%)
	Secondary	21 (42%)
	Graduate and above	09 (18%)
Socioeconomic status	Lower	19 (38%)
	Middle	29 (58%)
	Upper	02 (04%)
Residence	Urban	09 (18%)
	Rural	41 (82%)

Table 2: Proportion of participants accepting different treatment options as part of ADs

Question in AD	Proportion of individuals agreeing
Would you like to make AD?	88%
Would you accept admissions in future if needed?	85%
Would you accept injectable medications in future if needed?	78%
Would you accept ECTs in future if needed?	53%
Would you accept physical restrains in future if needed?	38%

AD- Advance directive; ECT- Electroconvulsive therapy

Furthermore, we checked whether there was any association between different sociodemographic and clinical variables and the treatment choices the patients make [Table 3]. Comparison across different age groups, gender, educational status, and socioeconomic status did not yield any statistically significant differences with respect to treatment choices. Although individuals who had undergone ECTs and physical restraint in the past had significantly higher acceptance rates for future ECTs and physical restraint, respectively (P values 0.01 and 0.0297, respectively), P values are above the cut-off of 0.0019 as per Bonferroni correction ($0.05 \div 26$) and are not considered significant.

DISCUSSION

This is one of the very few studies to assess the attitude of Indian patients with major psychiatric illness toward psychiatric ADs. The findings suggest that a considerable proportion of our patients find it difficult to understand the concept of AD. However, the majority of those who could understand the concept were keen to make an AD, which is a welcome sign. Of those who were keen to make an AD, a considerable proportion of participants refused future hospitalization and chemical restraints. More importantly, about half of them refused future ECTs, and about two-thirds refused physical restraints in future.

Our findings are comparable to that of available Indian studies. Gowda *et al.* (2017) observed that 96% of the patients formulated their own ADs, about 57% preferred outpatient treatment over hospitalization, and about 58% refused future ECTs.^[11] Pathare *et al.* (2015) observed that around 25% of the participants did not prefer hospitalization, only 8% preferred to receive injectables, and 31% would refuse ECTs even if their treating doctor advises ECTs.^[10]

Studies conducted elsewhere have also shown similar results. Srebnik *et al.* (2005) demonstrated that 68% preferred other alternatives over hospitalization, 72% refused ECTs, and 81% documented their own preferred medication.^[13] Amering *et al.* (1999) assessed the attitude of psychiatric nurses and psychiatrists toward ADs and found that 75% of the respondents refused certain modalities of treatment. About 30% refused neuroleptics, and 75% rejected ECTs.^[14]

The combined outcome of this study and similar studies suggest that a considerable number of people with major mental illness would refuse hospitalization, physical restraints, and ECTs. These findings raise questions regarding the management of patients in future after AD is implemented and the possible difficulties healthcare providers and families may face in handling agitated patients.

Table 3: Association between different sociodemographic and clinical variables and the choices in AD

Variables	Subcategories	Choices made in AD			
		Wish to make AD	Would agree for hospitalizations	Would agree for ECTs	Would agree for physical restraint
Age	Young	90%	92.30%	50.00%	38.46%
	Middle age	73.33%	71.42%	57.14%	35.7%
	Elderly	100%	85%	52.50%	37.5%
Sex	Males	85.19%	86.36%	38.89%	27.78%
	Females	94.44%	83.33%	63.63%	45.45%
Education	Primary	86.67%	78.57%	51.85%	21.43%
	Secondary	90.47%	83.33%	52.50%	44.44%
	Graduate and above	88.89%	100%	53.84%	50.00%
Socioeconomic status	Lower	92.30%	76.92%	53.84%	30.77%
	Middle	86.67%	88.89%	51.85%	40.74%
	Upper	100%	85%	52.50%	37.50%
Residence	Urban	91.67%	85%	52.50%	39.39%
	Rural	77.77%	78.57%	57.14%	28.57%
Family h/o psychiatric illness	Yes	94.44%	79.31%	54.54%	45.45%
	No	90.47%	100%	51.74%	34.48%
ECT received in past	Yes	-	-	72.72%*	-
	No	-	-	27.78%	-
Physical restrains were applied in past	Yes	-	-	-	66.67%#
	No	-	-	-	25.00%

AD- Advance directive; ECT- Electroconvulsive therapy. * $P=0.0100$; # $P=0.0297$. Values in the bold are statistically significant observations

Our study could not establish any statistically significant association between different sociodemographic or clinical parameters and the attitude towards ADs. In addition, no variables significantly affected the treatment choices the participants make. Small sample size may be a reason for not getting significant P values in any comparisons.

The findings should be interpreted keeping the study limitations in mind. First being the sample size, as it is a pilot study. Second, the capacity to make AD was not assessed formally. No structured assessments of insight into the previous episode of illness or cognitive status were done—only clinical assessments were done and no tools were used. Detailed patient psychoeducation regarding ECTs and other treatment modalities could not be done due to time constraints, which might have affected decision-making by patients who were naive to such treatment modalities. The tool designed to assess the attitude of subjects toward AD was not validated.

One interesting observation was that some of the patients initially were leaving the treatment choices to the treating doctor, saying “I will do whatever you suggest.” However, they were encouraged to make their own choices, and the choices were recorded. The fact that a majority of the patients refused ECTs and restraints is evidence for the argument that patients have not given desirable responses to please their doctors.

The strengths of the study are that it is one of the earliest efforts to assess the attitude of Indian patients towards

AD and the practical issues to be considered before implementing AD. Unlike some previous studies, this study was done in a general hospital psychiatry unit, making the findings more generalizable. This study, unlike some previous studies, included patients who were clinically asymptomatic and hence were competent to make ADs. The study was conducted in a private large-scale tertiary hospital; as mentioned earlier, the psychiatric services in this hospital are provided free of cost or at a minimal expense. Hence, it can be argued that patients visiting this hospital represent the Indian patient community at large.

CONCLUSION

Around 10% of the patients did not understand the concept of AD. The majority of the patients were willing to make ADs. Half of the subjects in their ADs refused to undergo ECTs, and about two-thirds refused physical restraints in future episodes of illness.

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Conflicts of interest

There are no conflicts of interest.

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