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What do service users want? A content analysis of what users may write in psychiatric advance directives in India

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ABSTRACT

Although psychiatric advance directives give service users control over their care, very few studies exist on the content of PADs. This paper aims to contribute to this evidence base by presenting the content of psychiatric advance directives in India.

Participants were 75 clients seeking outpatient care at a mental health services organisation in Tamil Nadu, India, who agreed to draft a PAD.

Most clients were comfortable with appointing a representative (usually a family member) to make decisions on their behalf during a period of decisional incapacity or relapse, were willing to accept admission to the hospital/clinic and take medication if required, wanted to have a trusted person to discuss their mental health problems. No client used the opportunity to outright refuse treatment.

This study highlights an important first step in improving the quality of mental health care by documenting user preferences for care in India. More in-depth research is needed to elicit rich descriptions of experiences of care and user-centred understanding of rights.

1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has encouraged a shift from dominant models of guardianship to models of supported-decision making in a number of mental health laws worldwide. Central to the notion of supported decision making is Article 12 of the CRPD, which states that all persons with disabilities should be provided support, where needed, to exercise their legal capacity in all domains of civil, political and judicial life. This includes the right to make decisions about health care and treatment processes, and have them respected by professionals.

Psychiatric Advance Directive (PAD) is one tool to facilitate supported decision-making. PADs are a tool for recording and implementing service user preferences in advance of periods of decisional incapacity throughout the course of mental illness (Campbell and Kisely, 2009; Henderson et al., 2008). PADs can either be instructional (e.g. specify treatment and personal decisions while in a period of decisional incapacity) or elect a nominated representative (proxy decision maker) to take decisions during this period of incapacity. Furthermore, preferences can be expressed and articulated independently or via facilitator (typically a health worker or peer support worker). PADs can enhance dialogue between health care professionals, family members, and service users, improve treatment adherence and continuity of care, and reduce the likelihood of hospitalisation and coercive care (Elbogen et al., 2007; Jankovic et al., 2010; Srebnik et al., 2005; Swanson et al., 2006).

Globally, although a sizeable evidence base exists on the benefits and barriers to PAD implementation and use (Henderson et al., 2008; Shields et al., 2014) we know very little about the content of PADs (Srebnik et al., 2005), with only two studies conducted in the US (Amering et al., 2005; Srebnik et al., 2005) and one study in India (Kumar et al., 2012) which detail the content of PADs. Understanding the information provided in PADs is important for anticipating future service user needs, as well as

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Table 1
Sample characteristics ($n = 75$).

Variable	*N* (%) or Mean (SD)
Age in years	38.7 (10.9)
Sex (female)	44 (58.6)
Geographical setting (rural)	43 (57.3)
Education level*	
Illiterate	5
Up to VIIth standard	22
Up to Xth standard	24
Up to XII standard	9
Up to graduation	6
Diploma holder	2
Diagnosis	
Depression	6
Bipolar disorder	4
Schizophrenia and/or psychosis	7
Alcohol dependence	4
Social anxiety disorder	1
Personality disorder	1
Number of clients currently taking medication regularly	70 (93)

* Indian education system classification N.B: missing data; education $n = 7$.

for broader service planning. Furthermore, from the service delivery side, instructions articulated in a PAD may shape individual care, and patterns identified across PADs could shape or catalyse the need for adaptations/different services and policies (Srebnik et al., 2005).

India is one example of a LMIC currently undergoing mental health legislation reform. The revised Mental Health Care Bill (Ministry of Health, 2013) adopts a more rights-based approach to care and has made an explicit provision for PADs as a way to promote supported decision-making. The draft legislation provides for a PAD where a service user can (a) specify the type of treatment a service user may want (b) the type of treatment a service user may not want and (c) the person the service user wants to make decisions as a nominated representative (proxy decision maker).

However, as the reform is current, research on PAD implementation is scarce in India, given that it is a relatively new concept in both scientific and academic discourses. There have been two studies from the state of Tamil Nadu (Kumar et al., 2012; Shields et al., 2013), which have documented completion of PADs and unpacking the concept of PADs with service users. However, there has been anxiety amongst mental health professionals about PADs, including how the process of completing and using a PAD will work, whether it will become a barrier to care and treatment (Kala, 2013; Sarin et al., 2012). Doubts have also been expressed whether PADs are appropriate for the Indian service and cultural context.

In order to implement PADs in a contextually relevant way that is feasible for service users to demand and complete, additional evidence is needed to facilitate conceptualisation, operationalisation and application of PAD in India. It is unclear whether patterns exist in PADs, and if so, what direction these patterns point to. In an effort to build the PAD evidence base in India and within LMICs and to provide a voice to service users in care planning, the aim of this paper is to present the content of PAD created by outpatients in Tamil Nadu, India.

2. Methodology

2.1. Design

This paper presents quantitative data from a study assessing the feasibility and utility of PADs, including the analysis of content of PADs documented by clients. Another paper (Shields et al., 2013) reported data from qualitative interviews (with a proportion of clients who completed the PADs and their carers) conducted before and after completing a PAD.

2.2. Sample and setting

2.2.1. Study location

PADs were completed in outpatient clinics run by The Banyan, a non-profit mental health service organisation in Chennai, Tamil Nadu, India. The Banyan runs services throughout the state of Tamil Nadu, largely concentrated in the city of Chennai and provides a full range of services including preventative services, community-based care, tertiary care, rehabilitation and re-integration, community awareness, and policy advocacy.

2.2.2. Recruitment and sampling

Clients enrolled in the study were existing outpatients in The Banyan. Clients received combinations of pharmacotherapy, psychotherapy, and social care at two urban clinic sites, and one rural clinic site. From March 2013 to June 2013 during outpatient clinic times, health workers trained as facilitators screened clients who were 18 years of age or older. Clients who had been diagnosed with a severe or chronic mental illness such as bipolar disorder, recurrent mood disorder, psychosis or schizoaffective disorder and were able to understand speak, and/or write in Tamil or English were included in the study. The clinic does not maintain formal ICD-10 diagnosis but uses working clinical diagnosis made by the treating psychiatrists. Clients having a diagnosis of mental retardation, or organic psychosis, and those having acute form of illness, which made their participation difficult, were excluded during screening. To include clients in the study, the research team consulted the psychiatrists at the Banyan to assess current symptoms and capacity. Selected clients were then asked if they would be interested in completing a PAD after being briefed by the health worker. The sample was stratified by gender and location (i.e. equal numbers of clients living in urban and rural settings). This was done to ensure that clients living in rural areas and women (who are often underrepresented) were offered the opportunity to write a PAD.

2.3. Training and procedure

Before commencing the study, health workers (case managers, social workers, psychologists, psychiatrists) at the Banyan were trained for facilitating PADs. The training program focused on providing basic information about PAD, its relevance for clients and staff, methods for facilitating the PADs, and how they are used. This training was expected to equip the facilitator (health worker) to introduce the PAD to the client, communicate its potential value to the client, and guide the client through the process of writing a PAD during the outpatient consultation or at an agreed upon time. For facilitating the PAD, we used PAD forms. On request, trained facilitators assisted clients in writing the PAD. Depending upon literacy level, clients either wrote their PAD or dictated their preferences to PAD facilitators.

2.4. Data collection and statistical analysis

Demographic information (age, sex, rural/urban living situation, marital status) and clinical characteristics of the clients were collected from the carers as well as from the clinical records of the clients. Data was extracted from PAD forms and entered in SPSS. Contents of the PAD forms were analysed by using MaxQDA.

2.5. Ethical considerations

We received local ethical approval from the external research review committee for The Banyan. Consent to participate in the