International Journal of Law and Psychiatry 56 (2018) 17–26

Contents lists available at ScienceDirect

International Journal of Law and Psychiatry

Factors influencing advance directives among psychiatric inpatients in India☆,☆☆

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ARTICLE INFO

Article history:
Received 21 March 2017
Received in revised form 30 June 2017
Accepted 10 October 2017
Available online xxxx

Keywords:
Psychiatric advance directives
India
Insight
The Mental Health Care Act-2017
Capacity

ABSTRACT

Objectives: Advance directives are documents stating treatment preferences in case of future lack of decision making capacity. In India, as in many other countries, legislators advocate Psychiatric Advance Directives (PADs), while evidence on its use is limited. This study examined factors influencing PADs by gathering inpatients perspectives on PADs at discharge and investigating patient characteristics associated with the expression of treatment wishes in PADs.

Methods: We conducted a hospital based descriptive study in Bangalore. 200 patients were included. The Mini International Neuropsychiatric Interview, CGI-S and CGI-I (Clinical Global Impression scales), the Insight Scale-2, and an Illness insight assessment were completed within 3 days of admission. We used the Bangalore Advance Directive Interview (BADI) to assess attitudes towards PADs. 182 subjects were reassessed within 3 days of discharge, along with an interview on their perspectives on PADs.

Results: 67% welcomed the need for PADs in India. 95.6% made their own PADs. 80% followed their doctors' advice in their PAD. Subjects lacking insight or remaining symptomatic at discharge opted significantly more often against ECT, antipsychotics, and inpatient care. Linear regression showed that low socio-economic status, unwillingness to stay in hospital, and having received ECT before were inversely associated with the expression of treatment wishes in PADs.

Conclusions: This study's findings are relevant for India and Western countries alike while generating legislation including patients' perspectives. A majority of patients favoured PADs. Absent insight, severe psychopathology and incomplete recovery may negatively influence the way PADs are completed. Therefore, clinicians must assess patient's capacity to formulate PADs carefully, as capacity may significantly influence patients' views. The timing of when to formulate one's PAD within the illness process may be essential.

1. Introduction

In India, the concept of Psychiatric Advance Directives (PADs) is outlined in The Mental Health Care Act -2017. This Act came into force on the 7th April 2017 after the president of India signed the Bill. India is one of many countries in the process of including Advance Directives in health legislation. The main reason for this is political and was developed after India ratified the United Nations Convention on Persons with Disabilities (UNCRPD) in October 2007, rather than based on evidence supporting the efficacy of Advance Directives (Sarin, Murthy, & Chatterjee, 2012). The current Act was introduced to overcome the inadequacies of the existing Mental Health Act, 1987. It was necessary to align and harmonize the existing Indian laws with the principles of human rights as defined in the United Nations Convention on Persons with Disabilities (UNCRPD). Advance Directives are a key element in the new mental health legislation in order to achieve this harmonization.

Advance Directives are documents made by patients with decision-making capacity stating treatment preferences in case of future lack of capacity (Hoge, 1994; Lepping, 1993; Srebnik & La Fond, 1999). The concept of Advance Directives originated from the "Right to die movement" in the United States nearly half a century ago. Especially with

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☆☆ Role of funding source: EO Noorthoorn is funded by the Dutch government to collaborate with researchers for 2014-2016, grant 5152 Ministry of Health, Wellbeing and Sports. For all other authors: none

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https://doi.org/10.1016/j.ijlp.2017.10.002
0160-2527/

regards to end of life decisions Advance Directives are integrated into health care in many countries. Initially, health care decisions were determined by professionals following principles of beneficence (Oddi, 1994). With the Psychiatric Self Determination Act (PDSA) passed in 1994, the United States formulated the first legislation that included patients' rights to make decisions on aspects of their own treatment. Since then many countries around the world have developed legislation that allows patients with capacity to make advance statements about their treatment wishes in case of future incapacity. This includes decisions on psychiatric treatment, although mental health legislation often restricts such choices (Carson & Lepping, 2009).

The former Indian Mental Health Act of 1987 contained no provisions for a Psychiatric Advance Directive (PADs), neither by the patient nor by a Nominated Representative. In contrast, The Mental Health Care Act, 2017, outlines in Section 5 that an Advance Directive in Psychiatry must comprise the following aspects:

1. Treatment modalities desired (treatments wanted by patient)
2. Treatment modalities not desired (treatments refused by patient)
3. Nomination of a surrogate decision maker in case of patient's incapacity

Such an Advance Directive needs to be written in the presence of two witnesses and a certificate of competence must be obtained from a General Practitioner or a Registered Medical Practitioner. According to The Mental Health Care Act-2017, capacity will be assessed as follows: A person has capacity if the person has the ability to:

a) understand the relevant information to make decisions regarding treatment or admission or personal assistance; or
b) understand the consequences of making a decision or lack of decision on the treatment or admission or personal assistance; or
c) communicate the decision by verbal or non-verbal means of communication.

No formal capacity assessment tool is required. The PAD needs to be submitted to the District Mental Health Review Committee (MHRC). However, registration is not absolutely required to make the PAD legally binding. The draft allows the provision of amending, cancelling or revoking the PAD at any point in time. A blanket refusal of any kind of treatment is considered invalid, unless approved by the district panel of the MHRC. The PAD therefore requires a clear formulation of the patient's preferences and refusals. An appeal is to be made before the MHRC in cases of requests to overrule the PADs. PADs written within 72 h of receiving emergency treatment will be considered invalid (The Mental Health Care Act-2017; Sarin et al., 2012).

There are very limited existing studies on PADs from India. A study from the SCARF foundation shows psychotic patients with a long-term illness were able to make valid PADs irrespective of their education and locality of stay (Kumar et al., 2013). In another 2013 study, patients decided about treatment (passive, active, and collaborative) depending on the situation and decision at hand, and had high levels of self-efficacy (Shields et al., 2013). Another recent study from south India by Pathare and his group investigated service users and their families' opinions about the new legislation. In that study, most users agreed to formulate a PAD and were comfortable in appointing a nominated representative (Pathare, Shields, Nardodkar, Narahimhan, & Bunders, 2015). PADs are, however, not yet common practice. There is limited empirical experience to understand what is necessary to successfully implement advance directives into psychiatric care in India (Sarin et al., 2012). Legally, all adults, including those with mental illnesses, are presumed competent to make health care decisions unless proven otherwise. In India, a family commitment is required for admission because of the obligation to take care by family members in hospital. This constellation may well be expected to lead to more patients or family members filling in PADs (Shields et al., 2013).

The inclusion of Advance Directives in the law is burdened by a number of issues, especially in middle and low-income countries such as India. The literacy of patients in mental health care can be limited. Many may not understand the merits of appointments made in Advance Directives. It is often unclear to which extent Advance Directives are really understood by patients or their caregivers. Once back home, they may forget these appointments or it may not be feasible to uphold them due to economic restraints. Experience in using Advance Directives remains scarce as resources to draw up Advance Directives with patients or their next of kin are scarce. In a systematic review that included studies primarily from high income countries, Lepping et al. found that across inpatient and outpatient psychiatric populations the weighted average proportion of patients with incapacity was 45% (95% confidence interval (CI) 39–51%) (Lepping, Stanly, & Turner, 2015). This indicates that assumptions about patients' capacity to make Advance Directives should be approached with caution and careful assessments of capacity are required before such directives become valid and applicable.

Some authors have criticized placing too much value on capacity at the neglect of beneficence and good outcome (Lepping & Raveesh, 2014), but despite all criticism capacity remains the cornerstone of autonomous decision making in most legislative frameworks around the world. It is important to delineate capacity from competence. Mental capacity is a multidimensional construct with capacity in the centre of an individual's ability to make autonomous decisions (Okai et al., 2007). Competence is a legal term determined by a court. In contrast, capacity is a medical term usually used by mental health professionals who determine a person's capacity to make certain choices (Lepping, 1993).

Another complex issue is the severity of the patient's psychiatric disorder, which may be different when the Advance Directive is drafted compared to when it needs to come into effect. Severe Mental Illness (SMI) is often characterized by alternating periods of capacity and incapacity (Srebnik & La Fond, 1999). Incapacity is a common feature of an acute exacerbation of mental illness with especially high prevalence of incapacity in acute mania and psychosis (Owen et al., 2013). During such exacerbations, patients often refuse treatment, but such refusals do not necessarily reflect the patient's true wishes, nor are they consistent over time (Owen et al., 2009; Owen et al., 2009). Therefore, PADs are relevant in mental illness with alternating capacity. PADs thus provide people with SMI the opportunity to convey their treatment preferences when they have capacity (Campbell & Kisely, 2009). Moreover, PADs can empower individuals to make decisions about their treatment and appropriate care, in turn leading to less perceived coercion and improved treatment motivation and adherence (Swanson et al., 2006). PADs allow timely and early interventions and provide the opportunity to help prevent the escalation of the patient's illness in the case of current and future admissions. Several recent studies (Thornicroft et al., 2013; de Jong et al., 2016) show that Advance Directives are associated with fewer compulsory admissions and less coercion.

In this context, Zelle (Zelle, Kemp, & Bonnen, 2015) recently stated that PADs are thought to “embody a recovery-oriented philosophy” by encouraging [patients] to preselect their treatments for times of future crises. How to embed PADs in treatment is essential. A large spectrum of advance statements emerged in a number of high-income countries like PADs, Facilitated Advance Directives, joint crisis plans, crisis cards, treatment plans, wellness recovery action plans, Self-binding Directives, and Advance Refusals (Gergel & Owen, 2015; Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008; Lepping & Raveesh, 2014; Sarin et al., 2012). These vary in their goals, the level of involvement of the care provider, the role of the third party, the determination of competency or capacity, the nature of the advance agreement, and the degree to which they are legally binding (Henderson et al., 2008). It is important that Advance Directives are legally binding so that patients can be confident that their wishes are carried out. This also allows doctors to keep to the patient's Advance wishes without fear of retribution. Furthermore, as an added benefit it may reduce the need for coercive measures (Verlinde et al., 2016).