Advance directives and nominated representatives: A critique

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ABSTRACT

With the ratification of the landmark United Nations Convention on Rights of Persons with Disabilities by India, it was imperative to revamp the mental health-care legislation, among other changes. Most notably, a presumption of mental capacity has been introduced, which means a paradigm shift in the client and provider relationship. The Mental Healthcare Act, 2017 empowers all persons to make advance directives (AD) and nominate representatives for shared decision-making. Psychiatric ADs (PADs) also seem to improve the information exchange between the care provider and the service user. PADs may also be used as a vehicle of consent to future treatments. While drafting the PAD, the drafter must also plan how such directed care would be financed. Insurance companies have not been mandated to comply with ADs. In the eventuality that the drafter’s family refuse support for treatment specified in the PAD, the drafter would be left holding an unimplementable PAD. The AD saw its origins in the care of the terminally ill and decades later came to be utilized in mental health care. After nearly three decades of use in developed countries, evidence at best remains mixed or inconclusive. This review focuses on the AD from the Indian perspective.

Key words: Advance directives, India, Mental Healthcare Act 2017, nominated representative

INTRODUCTION

Advance directives (ADs) are documents written by any competent persons (except minors) in “advance” of an anticipated period of incompetence. Treatment choices, objections, values, and principles can be stipulated in such documents. These directives first came to the fore in “end-of-life” care. The Federal Patient Self Determination Act of 1991[1] in the United States first mandated all health-care facilities receiving any government funding to inform all inpatients regarding their right to make an AD. These ADs were legally binding but had low uptake and completion, possibly due to reduced clinician endorsement because the clinicians were involved less in the drafting stage and more at the implementation stage. Various countries and states today have separate guidelines and documents for psychiatric ADs (PADs).[2] The “Living Will” proposed by Kutner in 1968[3] heralded the era of advanced decision-making in end-of-life care. Terminally ill persons could give instructions regarding their future care, which then would be respected. Dr. Thomas Szasz, in his seminal article titled “The Psychiatric Will,” offers the patient a chance to retain a semblance of control over the times of incompetence. PADs also include the provision for health-care powers of attorney: a person could choose another person to whom...
such decision making could be relegated. This preferred proxy decision-maker is known as the Health Care Power of Attorney or Health Care Proxy.

THE STORY OF ULYSSES

The story of Ulysses/Odysseus is found in the ballads of Homer, the Odyssey. On one of his many long journeys, Ulysses embarks via sea to join the war efforts of the Greeks. He must pass the treacherous seas near the Isle of Sirens. Habitants of the Isle are mystical creatures known as Sirens that lure seafarers with their dooming music to dash their ships on the Isle’s rocks. A wise sage advises the cunning Ulysses to take some precautions against a certain fate. The protagonist wanting to hear the Sirens’ alluring songs, instructed his crew to tie him to the mast of the ship after he filled their ears with wax. This ensured that the crew were immune to the Sirens’ music and would also disregard Ulysses’ cries and commands to be untied. Seeing him struggle, they were to tie him to the mast even more tightly. This has come to be known as a Ulysses clause in mental health advance care planning. Needless to say, Ulysses’ cunning and preemptive instructions saw his safe passage through the treacherous seas, on to make many other successful voyages.

This story highlights a person mindful of looming danger could instruct how his freedom could be curtailed, and his basic human rights could be restricted in the interest of enjoying them at a later juncture. If this story were tweaked to be the working paradigm for today’s scenario of mental health care, the protagonist would be the mental health-care service user and the ship’s crew, care providers. The instructions would in today’s parlance be called as an AD and the effect of the Sirens as incapacity and serious consequences of the mental illness.

UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AND LEGAL CAPACITY

The United Nations Convention on Rights of Persons with Disabilities (UNCRPD)[6] is considered as one of the most important milestones in the disability rights movement. India ratified this convention in May 2008.[3] Article 12 of this convention enshrines in it an equal recognition before the law for all. It ushered in the paradigm change; capacity is to be presumed until proven otherwise. Those unable to make the required decisions should be supported to that effect with safeguards. This should continue until the person in question is able to make their own decisions even if it is to rid themselves of the supports they relied on. Article 12 elaborates on the states’ duties to provide the requisite supports so as to ensure the exercise of legal capacity by all persons with disabilities at par with others. Any such support must also take into account the supported persons rights, preferences, and values and must avoid all conflicts of interest. Before the UNCRPD and the Indian MHCA 2017, service users could not have given valid advance instructions and expected them to be followed. One of the barriers would have been the presumption of mental incapacity that goes along with a diagnosis of mental illness. However, this issue has been rectified in Section 4 of the MHCA, 2017.

PSYCHIATRIC ADVANCE DIRECTIVES IN MHCA 2017

Pursuing compliance with the UNCRPD’s article 12, the MHCA, 2017,[6] has introduced PADs in (Section 5–13) for all adults desiring to make one. It may also be written by the legal guardians of minor service users. The stipulated document is a hybrid of the instructional or the living will and the health-care “power of attorney.” The drafter wishing to make advance treatment decisions must write out on paper his/her prescriptions and/or proscriptions for future care and treatment. He/she may also additionally nominate a surrogate decision-maker referred to in the MHCA as nominated representative (NR) (Section 14–18). Such a document must be submitted then on to the Mental Health Review Boards (MHRB), where it must be registered. Once registered, they are to be followed during any interaction with mental health professionals except in an emergency.

A draft of the Central Mental Health Rules released in September 2018 by the Ministry of Health and Family Welfare, Government of India website, inviting comments, had a format[7] for the ADs. It required details such as prescriptive preferences, proscriptive preferences, and/or choice of NR. In addition, it required specification of any known drug allergies. Previous versions of the draft legislation of Mental Healthcare Bill (MHCB 2011, 2013)[8] had mentioned facilitation as a process of helping the service user to write their directive. The MHRB is provided as the appellate authority to adjudicate all disputes regarding PADs and NR. When assessing the contested PAD, the act lays down a set of five guiding questions as follows: (a) Was the drafter adequately informed? (b) Did the drafter anticipate the current situation? (c) Did the drafter have the capacity to make a PAD? (d) Was the PAD made under undue influence/coercion? and (e) Is the drafted PAD contrary to any existing law? The MHRB is also tasked with the provision of an online registry for these documents. Mental health professionals while providing care as per a valid PAD cannot be held liable for unforeseen consequences.

NOMINATED REPRESENTATIVE IN MHCA 2017

The MHCA, 2017 stipulates that every person who is not minor has the right to appoint an NR for taking treatment decisions during periods of incompetence. Written approval from the NR to be appointed is required. NRs need to consider the values, principles, and ethics of the service
users. They are to empower them with an understanding of the need for decisions, the consequences of the decisions, and those of not making any decision. They are to recuse themselves in case of any conflicts of interest. They are also the point persons to report on abuse or exploitation. They are to make decisions in the best interests of their wards. For wandering persons with mental illness, the representative of Director, Department of Social Welfare, is the default NR. A provision for temporary appointment of NR, by application to the treating psychiatrist, pending MHRB decision, has also been incorporated.

Further, the MHCA, in Section 81, stipulates that the central government is to create a guidance document for medical practitioners regarding capacity assessments. This will have an implication on PADS. The act also provides for an MHRB. Section 82 says that the MHRB has the powers to review, alter, or modify the PADS. Sections 89 and 90 also mention that PADS should be taken into account in all cases of supported admissions. Section 122 mentions that the Central Mental Health Authority is empowered to make and bring about modifications to the procedures relating to PADS.

### RESEARCH ON PSYCHIATRIC ADVANCE DIRECTIVES IN INDIA

We were able to find only five published studies from India related to ADs in psychiatry. Most notably, all these studies have been conducted in the South Indian states of Karnataka and Tamil Nadu. The first [10] examined whether persons with psychotic illness would be able to write valid PADS as per the provisions are given in the draft MHCB of 2011. Patients were recruited across multiple sites for a 1-month duration and along with their caregiver, given information regarding PADS using pictorial charts, in individual sessions, by research assistants. Of the total sample of 112, only 93 patients had the capacity and wrote PADS. All patients wrote valid PADS, among which >65% did so independently, 29% required “prompts,” and 6% required scribes. None of the patients used PADS for blanket refusal of treatment. The study sample was stratified to obtain equal representation from urban and rural areas and both genders. On average, it took about 20 min for the patients to write a PAD.

A qualitative study [11] examined responses from patients and caregivers before and after completing a PAD. Here, patients were chosen purposively. All patients reported an improvement in self-efficacy. However, of the 51 interviews, 39 were of patients and 12 were caregivers. Among caregivers, 11 reported disagreement with the presumption of capacity for their patients to make treatment choices. Six of these 12 caregivers reported misgivings about PADS, such as “PADs would add no value in giving any more control to the patients about their treatment”. Overall, caregivers expressed concerns regarding the misuse of these legal provisions by patients and also skeptical of the patient’s capacity to decide on their own treatments. A second paper from the same authors [12] reported quantitative data of 75 patients and a content analysis of their PADS. Most patients chose to retain their current treatments. These studies were done among the outpatient sample.

Another study [13] conducted in a premier institute, reported that among inpatients about to be discharged, most tended to make greater use of the prescriptive sections of PADS. This study evaluated nearly 200 inpatients who had received acute care and were ready to be discharged in the next couple of days. 67% of patients felt that PADS are needed, 24% were ambivalent, and 9% felt PADS are not needed in India. However, 96% of patients were able to formulate their own PADS. Among the patients who made PADS, 94% chose an NR, and most of them chose a family member as the NR. The patients, in the majority, agreed with the treatments initiated for them and retained mostly what they had been prescribed.

In another study [14] in Karnataka, 50 patients were interviewed in a private medical college. Of them, the majority insisted on retaining their current treatments and wanted to know more about PADS. The study included persons with Severe Mental Illness, schizophrenia, and bipolar affective disorder, who were asymptomatic for the preceding 3 months. Among the 45 patients who understood the concept of ADs, 89% were willing to make a PAD. Among them, 15% refused future hospitalization, 22% refused future chemical restraints, 47% refused future ECTs, and 62% refused future physical restraints. About the above study, a letter to the editor expressed concerns regarding the use of general instruments such as Clinical Global Impression (CGI) in assessing the severity of the illness rather than other quantifiable measurements using scales such as BPRS and PANSS [15]. It is prudent to note that the act does not recognize diagnosis, psychopathology, or severity as impacting capacity. Guidelines for assessments of capacity as per Section 81 are awaited. As of now, the concept of advanced decision-making for illnesses is unfamiliar to the patients, and qualitative open-ended questions would reveal only what information regarding PADS was dispensed during the study process.

An unpublished study was done in the National Institute of Mental Health and Neuro Sciences (NIMHANS) by the author SP examined the feasibility of PADS among outpatients attending the Psychiatry Department. These patients were in remission or minimally ill, with CGI–Severity scores of one or two, and thus stood the best chance at being adjudged as having intact mental capacity. Both accompanying family members and patients were educated in a standardized manner regarding the legislative provisions on PADS. Once educated, they were asked to make their PADS. The family members were then asked for opinions on the PADS made by
the patient. Key results were that the average time required by patients to make a PAD was about 15 min. This included the time taken to educate the patients regarding PADs. Furthermore, it was noted that among the 100 patients, two participants could independently write their PADs, one required facilitation only by reminding, and four others required facilitation as assistance in writing. The rest, i.e., 93 participants required both reminding and assistance in writing. Family members agreed to support their ward’s PADs only as long as it was effective and practical. Most family members opted for collaborative decision-making models, and majority recognized patients, family members, and treating professionals as the only stakeholders. Service users’ insight into illness did not show any trends with the PADs written or the opinion of the family members about the PADs. Mean years of education of the participants in this study was lower compared to that of those from another study\[10\] (eight vs twelve years respectively).

**ResearcH on PsychiapRic AdvancE DirEctives: internAtionAl perspectivE**

Realist systematic reviews identify critical theoretical mechanisms that make the intervention viable, examine the contexts and conditions of its implementation, and assess the overall integrity of the proposed theories. They are of special utility in examining complex multistage interventions.\[16\] Nicaise \textit{et al.} examined PADs as a complex intervention in a realist systematic review.\[17\] The existing literature revolves around three broad functions as follows: (a) enhancement of autonomy and self-direction, (b) improvement in dialogue with care providers and better therapeutic alliance, and (c) an integration of care systems and services.

**Autonomy**

PADs can function as a vehicle for autonomous treatment decisions made by a competent drafter to be carried over into their period of incompetence. Thus, in this manner, they function to enhance the individual’s autonomy when incompetent by substituting it with autonomous choices made during competence. The situational contexts may also differ along with the difference in time. One of the limitations of this extension of autonomy is that it does not have the capability of learning, correcting, and hence changing with time and context. Extrapolation of autonomy from a recent past may not be an ideal solution. The limitations of not being able to accurately anticipate contexts and potential situations and make appropriate choice of interventions cannot be completely overcome. If the entire intervention was outcome driven, as would be understood in obtaining a valid clinically useful PAD, then the autonomy needed to retain the ability to self-correct. Such self-correction would entail an ability to understand and evaluate anticipated contexts, have knowledge of possible options, and modification of responses based on values and principles. This could not be accomplished with the drafters’ extended autonomy. Neither can PAD manuals, full of hypothetical situations completely address the problem. Similar concerns are borne out in advance planning for the end-of-life care. PADs as a construct for autonomous care direction will retain this limitation. A method that the drafters can employ would be to regularly update their PAD to reflect changing contexts that they anticipate.

**Alliance**

Service users have reported improved levels of satisfaction after a better dialogue with their professional carer. PADs also seem to improve the information exchange between the care provider and the service user. Facilitation is a collaborative process that involves the patient and his/her health-care representative drafting a detailed advance care document. Such facilitated PADs stood a better chance of completion and clinical utility.\[18\] An external member facilitating the drafting of the Joint Crisis Plan along with Person with Mental Illness and their care provider has been evaluated in randomized control trials\[19,20\] in the United Kingdom and was found to be effective in terms of reducing involuntary admissions and improving therapeutic relationships.

**Implementation of Psychiatric advance directives**

There are multiple systems involved in mental health care, especially the involuntary care. Examples include law enforcement, judiciary, community, and health-care systems, etc. Differing perspectives from even one of these aspects of care would result in disruption in user experience. PADs being legally binding can be thought to have a benefit of improving interaction and dialogue between these stakeholders. It is expected that while providing care according to the legally binding directives, these services would be more integrated. Studies exploring PAD implementation have mostly restricted themselves to reporting completion rates, provider and user acceptance, readmission rates, visits to the emergency ward, etc., but not the fidelity of the services to the PAD. Integration of services at systemic levels can be inferred from studies that examine implementation of PADs. This is a lacuna in research thus far. A PAD may also be used as a vehicle for advanced consent to future treatments. When introducing legally binding directives, it is an apprehension among clinicians that it would be used to withdraw consent for all the future treatments. However, this apprehension is unfounded, as studies even in India report no outpatients refusing consent for future treatment,\[16,18\] but in one study from NIMHANS, 4 out of 174 inpatients did not want any future treatment for mental illness.\[18\] PADs stating refusal of all treatments could be specifically identified before registration and can be examined on a case by case basis.

Finally, the Ulysses clause is a directive within a directive to disregard expressed intent during decisional incapacity.
This means that it cannot be revoked or modified by the drafter when in use, i.e., in periods of incompetence. This is also referred to as the Odysseus pact or the self-binding directive. Its inclusion is a matter of controversy between clinicians and service users.

When providing proxy decision-making, two models may be adopted. First, the best interests model, in which the proxy’s decisions are guided by the best possible outcome. Second, the substituted judgments model which require the proxy to focus on the process rather than the outcome. The proxy has to be aware of the patient’s values and preferences, etc., and attempt to make decisions as he/she understood the patient would have. A mixture of these two models is also practiced.

In a Cochrane review of Randomised Control Trials (RCTs) on PADs, Campbell and Kiseley[21] were able to offer the following suggestions for the different stakeholders nearly a decade earlier. For the service users, they recommended that currently there is no evidence from RCTs that PADs are beneficial. For the professionals, they recommend further research on more extensive and collaborative forms of PADs. However, there is not enough evidence to recommend their incorporation into routine clinical practice. To the policy-makers, they opine that legally binding PADs are not beneficial. They recommend more collaborative PADs to maximize benefits.

CHALLENGES RELATED TO PSYCHIATRIC ADVANCE DIRECTIVES IN MHCA 2017

When examining the provisions and the current research, some challenges and difficulties in implementation come to the fore.

1. In the MHCA 2017, there is no recognition of or provision for facilitation or collaboration while drafting PADs. This leaves collaboration between the drafter and the professional entirely to the need felt by the drafter. Without the information exchange, the drafter’s awareness of available options and applicability in situations may be deficient. This may risk PADs with reduced clinical utility documents, from which coherent, implementable clinical decisions may not be easily deciphered. Our understanding of research reveals that most of the benefits associated with PADs are in the facet of improved consumer-provider relations. Improved patient satisfaction and enhanced therapeutic alliance are some of the benefits that may be missed out. We hope the incipient regulations promote facilitation and recognize collaborative decision-making

2. Clinicians see the Ulysses clause as an aid to the patient’s extended autonomy. Service user’s intentions recorded in the PAD can be understood to be their expected intent. When the PAD is in use, it is possible that the service user may express differing choices and intentions which can be referred to as their expressed intent. It must be acknowledged that both the expressed and expected intent may not be identical at all times. It can be anticipated that service users with PADs may contest its implementation when it is in use. The expressed intent of modification/revocation of the PAD which contains the expected intent of the competent drafter may interfere with its implementation. The absence of the Ulysses clause fails to address this issue. In its absence, the directive may become volatile and whimsical. Irrevocability may be advantageous during the implementation of the PAD

3. While examining contested PADs, guidelines for assessment by the MHRB are retrospective. This may result in further confusion and difficulty in implementation. Assessments of correct anticipation, capacity assessment, and adequate information in a retrospective manner seem implausible

4. While drafting the PAD, the drafter must also plan how such directed care would be financed. Insurance companies have not been mandated to comply with ADs

5. The MHRB is tasked with retrospective assessments when addressing disputes about PADs

6. PADs stating refusal of all treatments could be specifically identified before registration and can be examined on a case by case basis. It is imperative not to overvalue autonomy to the point of personal indignity, as were seen in the case of Russel Felming versus Scott Starson. In this case, a person with schizophrenia, when competent, used his PAD to refuse all treatments for his mental illness. This resulted in repeated conflicts with law enforcement due to the continued risk of violence to others. The PAD was found to be a valid transcription of his autonomy and was upheld by judicial systems. Ultimately, as the risk to others was not mitigated, the patient was incarcerated, but the circumstances could not compel treatment against his valid PAD.[22]

In a narrative review,[23] concerns have been raised about the conspicuous absence of AD in end-of-life care. Without the Ulysses clause, the duality of the expressed and expected intents could not be appreciated. In another review,[24] PADs are considered to be a wedge pushed between family members and the patients. The author warns against overvaluing autonomy over familial interdependence, especially in a country like India where families are the largest resource in caring for a mental illness. The risk of a patient refusing treatment in contradiction of his autonomy and was upheld by judicial systems. Ultimately, as the risk to others was not mitigated, the patient was incarcerated, but the circumstances could not compel treatment against his valid PAD.[22]

APEX COURT’S DECISION ON ADVANCE DIRECTIVE IN TERMINAL ILLNESS

Apex Court examined a Public Interest Litigation[25] on AD in terminally ill patients. Any person anticipating terminal illness and/or incurable coma may write an AD to be executed
in times of debility and incapacity. Once written, such a medical AD which has proscriptive and proxy components is to be deposited with the District Court’s digital registry, after attestation by two witnesses and the Judicial Magistrate of First Class (JMFC). The JMFC is tasked with providing copies of the AD to immediate family, representative of local government and family physician if any. Review of this AD will be undertaken by a medical board constituted within the treating hospital, comprising three specialists from six medical specialties with experience in critical care and at least 20 years of practice. Validation of withdrawal of treatment by this board mandates a second review by a similar medical board appointed by the District Collector. This board shall also mandatorily examine the patient, assessing decision-making capacity. Subsequently, the JMFC shall review the patient and authorize the withdrawal of treatment. Invalidation of the AD by either of the boards, allows the drafter’s well-wishers to petition the High Court by writ. An elaborate mechanism with checks and balances has been prescribed for ADs in terminal care. The same can hardly be said for PADs.

CONCLUSION

The MHCA’s provision on PADS and NRs has attempted to resonate with the UNCRPD’s Article 12 – “equal recognition before the law.” Barriers to the implementation of PADS in India are poor literacy, limited access to information, insufficient knowledge regarding mental health, mental illness, treatment and management options, and lack of human resources. These would impede PAD uptake and utilization. Possible solutions include provisions of facilitation and collaborative decision-making. MHCA 2017 statutes on PADS and NRs present a challenging yet golden opportunity to improve mental health care. Mental health professionals, especially psychiatrists, can routinely incorporate discussions with patients in remission regarding PADS. They may proceed to facilitate the drafting of such PADS. Patients can also be encouraged to nominate suitable NRs in the PADS. Discussions with primary caregivers about consenting to become NRs designated by the drafter would serve to legalize the unsaid, unwritten health-care proxy possessed by them.

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