



Advance Directives: identifying possible barriers in implementation and potential remedies

Abstract

Advance Directives (AD) are the legal right of every adult individual, who has the mental capacity to decide at the time of making AD, irrespective of one's previous mental illness. AD seem to be an answer for many concerns and make it possible for an individual to take or retain control over one's care by specifying treatment choices, well in advance and by naming someone as a Nominate Representative (NR) to make medical decisions once one is no longer able to do so. It can be expected that many barriers in the implementation of AD will be encountered that cannot be overlooked and active steps need to be taken to explore the possible barriers standing in the way of its effective implementation in our country. In short, it can be concluded that it is a challenging time for the mental health community as we live in a world of scarce workforce and millions of people need mental health services which demands urgent action. Despite the backing of the new law, we are well aware that we have a massive challenge on our hands. Hence, it is essential to accept the crucial role of country leadership in efforts to improve the mental health along with the critical part of civil society, media, and others to account for health outcomes. The purpose of this article is to collect the blinding flashes of insight to begin the prediction of barriers to AD's implementation and possible solutions.

Keywords: Legal Right. Mental Illness. Mental Health. Media.

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Received: 5 November 2017

Revised: 25 July 2018

Accepted: 26 July 2018

Epub: 25 January 2019

INTRODUCTION

In India, the Mental Health Act (MHA 1987) came into force in 1993,[1] and replaced the Indian Lunacy Act 1912, which had been in force for past 80 years. Although coming of MHA 1987 was in itself a great effort forward to substitute the century old Indian Lunacy Act, but subsequently many professionals' voices came up saying that it did not adequately deal with many important issues;[2-4] indicated strong need for some revisions. The advance of Mental Healthcare Act 2017 (MHCA 2017) is an act to provide for mental healthcare and services for persons with mental illness (PMI), and to protect, promote, and fulfil the rights of such persons during delivery of mental healthcare and services and for matters connected therewith or incidental thereto.[5] MHCA 2017 can indeed be taken as a new milestone achieved to address the problematic issues surrounding mental health. It is divided into 16 chapters consisting of 126 sections, one of the most important features of this act is Advance Directives (AD), which has come into force for the first time in India, allowing the vulnerable population to make specific decisions for them. It allows competent persons to consent or refuse mental health treatment and designate someone, the Nominate Representative (NR), in advance of a mental health crisis, during which they may lose the capacity to make healthcare decisions.[6] The advance of AD in India is undoubtedly welcoming news; however, some experts[7]

look at it differently, arguing that our Indian population is not be ready for such AD.

DEFINING 'ADVANCE DIRECTIVES' FOR PSYCHIATRIC POPULATION

In India 'Advance Directive' means an AD made by a person under section 5(1) of MHCA 2017.[5] AD are legal rights, unless contrary to any existing laws, of every adult individual, who has the mental capacity to make the decision at the time of making AD in writing, irrespective of one's previous mental illness. In AD, one can specify treatment preferences or refusals and authorise/nominate a representative (NR), who can take future treatment decisions, on one's behalf in the condition when one loses the capacity to do so.[5]

POTENTIAL BARRIERS TO THE APPLICATION OF ADVANCE DIRECTIVES

What we know from western literature about possible barriers in the implementation of AD provides a valuable opportunity for Indian settings too. Understanding possible barriers and following most useful ways to remove these obstacles may help us a lot well in advance. Some of the salient observations based on the case studies and research (available on PubMed, Google research scholar, and other Internet sources) indicate towards some possible barriers which are presented in the present article. For the better understanding of the barriers

to the implementation of AD, these can be divided into four categories, including patient-related, clinician-related, system-related, and social barriers.

- (1) Patient-related barriers include a misunderstanding of AD; lack of resources necessary to complete AD; lack of someone to serve as NR, obtaining witnesses.[8] In addition to difficulty in understanding AD, the complexity of filling out the legal forms, having the documents notarised, filing the documents in a medical record.[9] Clinicians' lack of support for AD could represent a barrier to AD preparation as it is believed that most consumers need some support to complete AD;[10] moreover, doubt about their benefit[9] may make the condition even more difficult.
- (2) Clinician-related barriers include lack of access to the documents in a crisis, lack of staff training on psychiatric AD, lack of communication between staff across different components of mental health systems, lack of time to review AD.[11] Besides, barriers related to clinical or treatment factors are also important, including consumers' potential inappropriate treatment requests and desires to change their mind about treatment during crisis. In a study, barriers related to the work environment (e.g. a lack of communication between staff, lack of access to the document) were endorsed at a higher rate than those related to clinical factors.[11] Due to increasing workload, mental health professionals often experience 'compassion fatigue'. [12,13] Hence, lack of trained mental health professionals also needs to be taken care of in our settings.
- (3) System-related barriers, empowering service users with AD in Indian setting will depend significantly on the availability of mental health services, for the same existing infrastructure for mental healthcare seems inadequate. For instance, high treatment gap (i.e. estimated 90%);[14] along with no or poor electronic medical record-keeping might lead to inadequate access to the documents in a crisis. Insufficient and limited treatment resources due to lack of availability of trained professionals, especially in rural settings and tribal regions, poses a significant challenge. As per an estimate even if all the psychiatrists available in the country work five days a week (eight hours a day), provide consultation to a patient for 15-30 minutes over a period of a year, then they would only be able to help for about ten to 20% of the total burden of severe mental disorders.[14] Increased professional burnout may lead to many concerns, such as lack of time to review the AD documents [11]. Hence, the presence of these challenges demands that existing infrastructure for healthcare need to be strengthened.
- (4) Furthermore, some other barriers also seem to work directly or indirectly as barriers which are as follows (a) stigma associated with mental illness; (b) lack of awareness for mental illness; (c) reliance on faith healers; (d) caregiver burden; (e) homeless cases; (f) medico-legal issues, and (g) recent incidents of beating up clinicians. It is essential to look at what experts and research have said about these challenges to understand these concerns.

It has come to light that nine out of ten people with mental health problems have been affected by stigma and discrimination;[15] lack of knowledge about the mental

illnesses poses more challenges,[16] such as delaying treatment or not seeking treatment at all; making an AD seems too far-fetched in such cases. Moreover, to the surprise, in a study, Mushtaq and Margoob[17] stated, "In 1996, 73% of the total patients would visit a faith-healer before seeking psychiatric help and more-so in rural areas (87% in rural and 59% in urban area), while as in 2005, 68.5% (84% in rural and 53% in urban) of the patients seeking treatment visit faith-healers first".[17] In our country, almost all the care of PMI is being provided by family members, in short, it can be said that family members act as a primary caregiver. Caregiving is generally considered as a cumbersome work as burden or stress of caregiving is reported to be experienced by almost 80% of people in the caregiving role.[18] It is also observed that individuals who have a mental illness and their families are also vulnerable to face legal issues.[19] A combination of caregiving burden and vulnerability to legal hassles makes the situation even more complicated. Furthermore, in the case of homeless patients, the unavailability or poor accessibility of the institutional care is also a challenge.[20] As per an estimate, there are about ten to 15 thousand homeless PMI living only in a state,[20] let alone the whole country. Recently, it has also been observed that violence against medical professionals has increased,[21,22] that may impede therapeutic relationship and communication. A combination of the very nature of the psychiatric illness and these factors lead PMI to suffer doubly; they not only struggle with the disease-related symptoms and disabilities but also challenged by inadequate support from family, professionals, and community, which might ultimately lead to underutilisation of available mental health services.

It is essential to break down these barriers because adequate communication within the mental health professionals and with patients and families is essential in providing holistic care to this vulnerable population. All these factors also indicate towards the fact that PMI's right is easily violated; hence, treating team, family, as well as the community as a whole need to sensitise towards their responsibilities and rights of PMI.

HOW CAN PSYCHIATRIC ADVANCE DIRECTIVES BE EXECUTED SUCCESSFULLY?

Although, insight from the world literature seems to help, yet merely viewing AD with western experiences is not going to work in our setting where the family members provide almost all the care. Thinking about future difficulties and their possible culture-specific solutions must be made at this point concerning a right (AD) that is new and needs more discussion than can be provided in the literature. Shields *et al.*[23] conducted a study to explore the feasibility and utility of AD in India, with a focus on the need for individual control over decision making and barriers to implementation, by exploring views of its central stakeholders, service users, and careers. They concluded that the introduction of psychiatric AD in India appears to be associated with positive outcomes for some service users; however, there is a need to understand better how this tool can be adapted to suit the care context in India better, and hold meaning and value for service users to

complete.[23] Thus, while AD are a highly desirable clinical tool for collaborative decision making between PMI and the treatment provider, at this time, more is needed to be done in India.[24] As prevention is better than cure, it is imperative that we be aware of the dangers of possible barriers and if the concerns as mentioned above are correctly addressed, it will be highly beneficial in the welfare of PMI.[25] Below mentioned suggestions seem to help as potential remedies to barriers mentioned above in Indian setting.

Awareness programmes

Need to raise awareness about AD among PMI, their family, and other concerned members are essential as research has already shown that AD comprehension is central to achieving benefits from AD.[9,26] Clinical staffs also need to be aware because AD require the ability to grasp somewhat tricky and abstract concepts, such as fluctuating decisional capacity and future preferences for treatment.[27] It is to be remembered that the earlier research findings indicate that those who complete such documents generally do not receive assistance in understanding or discussing their underlying goals and values.[28] So, it is required to be ensured that these people get all help to clarify their indecision. Also, there is need of awareness programme to reduce the stigma attached to mental illness through a change of attitude and public education by government officials or some local non-governmental organisations (NGO), particularly in the rural areas. Awareness may be spread through mass media programmes, such as television and radio talk and newspaper articles in the local language.

Availability of help in AD making process

It has been found that lack of resources necessary to complete AD,[8] is one of the barriers to the implementation of AD. Elbogen *et al.*[27,29] found that the manualised AD facilitation significantly improved patients' competence to complete AD, as well as patients' treatment decision making capacity in general. Another research has recommended utilisation of a computer assist program (AD-Maker) to facilitate AD completion.[30] The very exercise of preparing AD and discussing it with a mental health professional may enhance therapeutic alliance and improve treatment engagement.[31-33] Some patients may wish for their NR or families' interests to be taken into account in decision making rather than expecting NR to base decisions solely on the wishes of the patient using a substituted judgement standard;[28] others may doubt about different issues; hence, availability of help in AD making process is needed and can be recommended.

Accessibility of continuous helping system

Generally, it is believed that the very process of preparing these documents will enhance patients' sense of trust and collaboration with providers, thereby enhance treatment compliance.[34,35] However, once AD are completed, planning is typically considered complete and systematic effort to reopen the conversation as a person's health declines is rarely made.[28] Besides, while selecting an NR, a patient authorises someone to speak on his or her behalf; however,

AD typically do not include directions for NR or healthcare professionals about treatment preferences.[28] Moreover, mental health professionals often have limited information about those patients who come in hospital emergency departments;[36] nonetheless, these are the typical settings in which clinicians are called on to make critical management and treatment decisions with whatever limited data available. As with AD, clinicians could gain immediate access to relevant information about individual cases and thus improve the quality of clinical decision making.[27] Hence, to take full advantage, quick and fast access to the medical data as well as AD access on 24/7 basis need to be made available to all the stakeholders through the Internet. So that, mental health professionals quickly and securely gather the clean and complete data they need via the web, paper, or phone. The government needs to ensure that PMI, family members, as well as mental health professionals get all assistance that is required at the time of psychiatric crisis.

Answers to questions about legality and liability

It is generally accepted that PMI is at higher risk of violation of their rights. Moreover, PMI and their families are also vulnerable to face legal issues, and the very nature of the illness may limit accessibility and effective utilisation of legal services.[19] It is prerequisite that during the making or revoking of AD, person needs to take care of the existing laws and must follow the regulations made by the central authority.[5] Moreover, it is the duty of the person and his NR to ensure that concerned mental health professional has access to AD, when required. Medical professionals in charge of a person's treatment have to give treatment, following valid AD.[5] However, neither professional shall be held liable for any unforeseen consequences on following a valid AD, nor one shall be held liable for not following a valid AD if he has not been given a copy of the valid AD. In short, it can be said that MHCA 2017 [5] makes the direction of every stakeholder but some can be sceptical about these rules and duties. Some researchers also believe that AD will present a wide range of legal and ethical problems, making them impractical in practice.[37]

So, questions about legality and liability need to be addressed; a workable system is needed, not only for the advocacy of patient but also to keep an eye on the ill-treatment given by untrained professionals and 'peer fakir' faith healer that is essential to ensure that PMI and family members be aware of the legal rights and provisions. Recently, Hamza *et al.*[19] recommend free legal aid services in all hospitals, especially psychiatric hospitals across the country having a multidisciplinary team, to provide various services, such as legal advice, referral services, and even to provide brief mental health services.[19] Hence, it is crucial that coordinated legal and legislative work with other agencies need to start awareness programmes aimed at providing this new information through facilitated community dialogues on a regular basis along with developing and distributing educational training material, explaining patients and families what the law and best practice comprise, including their rights and responsibilities. Besides, the government may take initiatives to sensitise legislators, policymakers, community

leaders, law enforcement personnel which will help in better response from different sections of people towards AD.

Association with family members in the decision-making process

In India, more than 90% of patients with chronic mental illness live with their families.[38,39] It is also rightly pointed out that the family members need to be involved to the most significant extent in the mental healthcare and family support should be encouraged as it provides moral, emotional, and physical support to PMI.[40] Research has proven that many people, particularly those from non-western cultures, conceptualise the broader social network as the basis for treatment decisions, not the wishes and needs of the individual. Patients may also choose to delegate their autonomy to a family member, religious leader, or others, and defer discussions about prognosis and treatments for cultural or other reasons.[28] Moreover, research also suggests that many patients do not expect NR to follow their traditional AD rigidly but instead intend for NR to exercise judgement to determine the course of care when there is insufficient information available or for extenuating circumstances.[28] Hence, more extensive involvement and communication among mental health professionals, the patients, and their families are needed in our settings.

CONCLUSION

It can be assumed without doubt that PMI is at higher risk of violation of their rights; AD provide them the power to decide for themselves. AD empower in the recovery from mental illness, enhances interaction between individuals and their families, friends, healthcare providers, and other professionals. It is high time to give a collective thought to the fact that effective implementation of AD requires an understanding of the barriers in the Indian context. The present review provides a pathway to identify the possible barriers and their potential remedies based on many sources. Hence, we recommend that in our settings, every effort should be made to implement AD to empower our citizens by giving them the right to self-determination at the time of psychiatric crisis and strongly recommend that suggestions given by family members should also be taken into consideration to facilitate safe treatment/care and flourishing their bond of care. Besides, provision should be made to provide free legal aids to this vulnerable population in hospital settings.

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Nehra DK, Gupta R. Advance Directives: identifying possible barriers in implementation and potential remedies. *Open J Psychiatry Allied Sci.* 2019 Jan 25. [Epub ahead of print].

Source of support: Nil. **Declaration of interest:** None.