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DO WE NEED "ADVANCE DIRECTIVE" IN INDIAN SETTINGS?

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ABSTRACT

Incorporation of the concept of advance directive under the Mental Health Care Act of 2017 has raised many eyebrows. This concept, which is often being termed as the mimeo-graphic representation of the mental health acts of western countries, is supposed to be hard in finding relevancy in the Indian society. The question-mark is being put, not only regarding our preparedness over this issue but also over its appropriation in specific conditions. In times where we have not been to challenge satisfactorily the stigma and discrimination against the mentally ill, and are still trying to provide them with minimal facilities, the issue of Advanced Directive (ADs) would be difficult to be imbibed among the masses, whose knowledge and understanding of mental illness is still in destitute state. Furthermore, lack of clarity around ability to carry out or revoke the ADs and its related concepts like that of nominated representative, is going to make the task no easier. The idea of Advanced Directive has found it difficult to be consistent in the western societies, where it originally took birth and has been posed with many hindrances. As such, inadequate attention towards various associated logistical concerns may present to substantial hindrance in proper implementation of the ADs.

INTRODUCTION:

Some experts[1] have cited their apprehensions regarding the preparedness of our Indian population for such ADs into certain queries, that include (i) what if, a person with mental illness may revoke, amend, or cancel ADs many times in a day, and family members find it difficult to handle such situations; (ii) what if the patient has been written costly treatment or private/corporate hospital (which family cannot afford) in ADs, in that case who will bear the burden of the costly treatment. Eyebrows have also been raised in the world literature regarding concerns that include; (iii) what if, some of these patients refuse treatment or supervision because they lack insight into their actual condition and undertake actions that are harmful to themselves or others and lead to extreme insult to their neighbors, may act sexually dis-inhibited, or embark on irresponsible financial transactions; such behavior may ultimately end up extremely destructive for individual self-esteem, private and social relations, career opportunities, etc[2] (iv) what if, when a person has the capacity to make a health care decision and has decided to refuse a vital intervention[3] (v) what if, person is suffering from illness having multiple episodes of competence and incompetence. Observations based on literature reviewed tends to provide answers for some of these points such as ADs need to be clear and relatively free of cumbersome jargon[4] because vague instructions result in conversations that produce equally vague expressions of wishes such as "Do not keep me alive with machines" or "Let me die if I am a vegetable."[5] If a person with capacity says no to a necessary intervention, it is generally considered the right practice to provide the information in writing afterward, for one's reconsideration[3] however, studies have already shown that the availability of ADs rarely leads to refusal of all treatment.[6] Besides, according to Appelbaum[7], ADs are considered particularly appropriate in the care of persons with mental illness, which is frequently characterized by alternating periods of competence and incompetence, because the directives afford these individuals an opportunity to state their treatment preferences when they are competent[4].

In the midst of these ambivalent claims, Dr. Alok Sarin[8] argued that "Furthermore, to be borne in mind is the fact that to date, India does not have a provision for the use of advance directive in end of life situations, so contemplating their use in mental illness situations may perhaps be a trifle premature"[8]. Despite these questions and answers we quite agree with the statements of Ratnam & collogues[9] "Treating patients within the framework of their pre-stated wishes will be a much more intricate and arduous task than most of the modern Psychiatric practice in India, but the difficulties, obstacles, and inevitable failures encountered will provide evidence of the delivery system's weaknesses and thereby contribute to its strength[9]

Historical background:

The concept of ADs initially evolved in the context of end-of-life treatment decision making[10] where it is anticipated that the person may be unable to express his or her desire or preference.[20] Traditionally, individuals with mental health problems did not achieve unison to become involved in their treatment decisions.[11] According to Jelena Jankovic et al.,[12] "In psychiatry, the concept of advance statements was first proposed by Thomas Szasz[13] in 1982 in the form of a 'psychiatric will' mirroring a 'living will' in other medical specialties and referred to advance decisions about involuntary treatment". In the United Kingdom (UK), the Mental Health Act 1983, the Code of Practice advised that change in a service user's opinion needed to be considered. The Mental Capacity Act 2005[14] is an act that describes advance statements in detail[14]; that was fully implemented on 1 October 2007. The first reported Court decision occurred in the United States of America (USA) in 1991, when a New York Court denied the authorization of electroshock therapy in the case of Rosa M (as cited by Morrissey[15]). Since 1991, the concept of AD has been legalized by 25 states of USA. As per Sarin, Murthy, Chatterjee,[10] consequently, in some countries, ADs have been promoted in the care and treatment of people with severe mental disorders. The inclusion of ADs in mental health settings is part of an international impetus towards the recognition and entrenchment of human rights for people with mental illness.[16] In short, it can be said that ADs has long been recognized in world history, but this is the first time any form of ADs stand to receive legal sanction in India.

Defining "Advance Directives" for Psychiatric population:

Experts (e.g. Appelbaum[7]; Winick[17]) believe that ADs are relatively new legal instruments that may be used to document a competent person's specific instructions or preferences regarding future mental health treatment, in preparation for the possibility that the person may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness. It allows individuals with severe mental illness to document preferences for future treatment if they lose decision-making capacity during a psychiatric crisis[18]. Zelle, Kemp, Bonnie,[19] clarified in the context of their country that ADs are written documents or oral statements that allow adults with decision-making capacity to declare their treatment preferences and/or to designate someone to act on their behalf, should they be deemed incapable in the future of making informed choices on their own. In short, it not only provides instructions for future care and outline personal choices; preferences for care, but may also specify the appointment of a proxy decision maker (NR).[20] In simple words, it can be said that the right of ADs allow one to choose a representative who is then entrusted with the responsibility of decision making for the period of anticipated incapacity, besides, to document preferences for future treatment if they lose decisional capacity during a psychiatric crisis.[4,18] In some countries like the UK, ADs are written documents or oral statements, whereas, in India, ADs are required to be legal written documents.

International Experience:

Lessons Learned from Research Findings of Developed Countries-

We know from the Western world that there would be many barriers to make ADs a ground reality, this knowledge can be used to improve our ability to think clearly and recognize the possible barriers beforehand and take appropriate actions, well in advance. As our understanding grows, we are recognizing that individuals are having varying degrees of knowledge about ADs and different perceptions of barriers in spite of having favorable views of ADs for mental health care[21] that can affect person's attitude about ADs, which has been proved by a Survey done to assess the knowledge of and attitudes about ADs from, person with mental illness, family members, hospitals' administrators, advocates by Wilder, Swanson et al., in 2012.

Some researchers reported that compliance with ADs had been far from perfect; treatment consistent with directives has been reported to occur 20 to 50 percent of the time.[22,23] Whereas, it is undoubted from the experts' perspectives that ADs have been hailed as a way of encouraging patients and treatment providers to discuss future contingencies and to negotiate mutually acceptable approaches to care.[4,24] What is surprising about the results of a study conducted by Swanson et al.,[25] that 66-77% of people say they would like to complete an ADs but only 4-13% of people have completed ADs in reality, indicating towards the need for identification and removal of barrier in its successful implementation. However, it would appear that fewer people than expected have made ADs; there may be some reasons for this. However, steps taken on time should make it possible to proceed farther, making "Advance Directive" a practical ground reality.

Do we need "advance directive" in Indian settings?

Even after decades, Dr. Wig's words, "we found now gross discrimination against people with mental illness in all spheres of life like job, housing, marriage, immigration, etc.; thus, greatly reducing the opportunities for mentally ill for their rightful participation in the society"[26], seem quite relevant and accurate in today's context. It has been proven that people with mental disorders are particularly vulnerable to abuse and violation of their rights[27] moreover, individuals with lower levels of education, low household income, lack of access to essential amenities are at high risk of mental disorder[28] that makes the situation more dreadful. It is not surprising that people with mental illness may perceive themselves, other people, and events around them differently than viewed by others or they used to see before the start of their illness; and sometimes, they may refuse treatment due to (a) absent insight, (b) severe mood symptoms, and (c) their symptoms might be compromising their decision-making[1] and often need to be admitted to a psychiatric hospital against their will for their own safety and/or that of others.[29] Hence, it can be said that there are two sides of the coin, one as seen by the person with mental illness and the other as seen by the treating professionals. For instance, on the one hand, many healthcare providers see involuntary hospitalization as necessary to prevent harm and protect those with Severe Mental Illness (SMI)[30]; on the other hand, studies have consistently found that people who suffer from SMI describe these interventions as frightening, disempowering, traumatic, and a barrier to treatment[31-34]. In addition, we need to accept that mental disorders in India are not necessarily experienced and understood in the same way as in Western countries[35-39] because in our setting, the vast majority of care is provided by the family[40] making it impossible to ignore the view of family members of the patients with mental illnesses (PMI).

Incidents of violence against doctors in India have increased in the last few years; news of doctors being roughed up, beaten and even killed by patients' disgruntled relatives are not uncommon[52,53]. Gupta, Kaur, Gupta[54] reported some possible reasons of violence against doctors including increasing distrust and suspicion in the doctor-patient relationship, relative's impression of neglect in patients' care, lack of communication, unnecessary investigations, delay in attending patient[54]; and have advocated stronger punishments, both for perpetrators of violence against doctors as well as medical negligence[54]. We hope that AD's use would increase mutual trust; and enhance communication among all the concerned and has potential to empower and protect a person with mental illness, family members, and professionals' trustworthy relationships and lead to decrease the need for legal involvement.

We are confronted with a wide array of questions that need to be answered and it seems to be the high time to make genuine efforts in providing answers to these questions, particularly in our settings, where there is a lack of an administrative structure to monitor the functioning and progress of the health programs. Fortunately, ADs seem to be an answer for these concerns and makes it possible for PMI to take or retain control over their care by specifying their treatment values and choices, well in advance, and by naming someone (can also be from family members) to make medical decisions once they are no longer able to do so. It can be forecasted that many barriers to the implementation of ADs will be encountered and cannot be overlooked and active steps need to be taken to explore the barriers standing in the way of practical implementation. Hence, it can be said for sure that like other countries, it is need of the hour that our country also focuses on the rights of persons with psychiatric conditions, and ADs implementation can be taken as a step forward to achieve that goal.

The Disposition toward ADs- a Critical analysis:

Observations based on the case studies and research indicate towards an amount of dilemma over the therapeutic benefits of the implementation of ADs. For some, these directives have been hailed as instruments for honoring patient autonomy, improving communication and ensuring participation in treatment decisions, and providing realistic alternatives to coercive measures[7,24,44] and decrease hospitalization and costly court involvement[45]. Whereas others believe that they present a wide range of legal and ethical problems, making them impractical in practice[15].

However, in an attempt to understand how the implementation of ADs might lead to therapeutic, psychological, and emotional benefits; we want to propose a possible mechanism that may reap us the positive effects, right from the very process of preparing these documents that enhance patients' sense of trust and collaboration with providers, thereby improving the therapeutic alliance and engagement with treatment[6,24]. Furthermore, many advocating for ADs believe that ADs can enhance autonomy (see Morrissey, 2010), with principle of autonomy itself stating that the patient alone has the right to decide what is done to them[46]; as well as has the significant potential of minimizing coercion and reactance by increasing the patient's feeling that one's treatment choices are respected, that ultimately lead to a therapeutic benefit[47]. Also, it empowers persons to participate in their future treatment decisions; that may help patients gain better access to the types of treatment that work best for them, especially during times when they are most in need of care but least able to speak for themselves provided that it is being followed by treatment providers[48-50]. Some therapeutic benefits are reported in world literature, including facilitation of preventative care, patient empowerment, prevention of future incapacity, reduction of stress and anxiety, recovery from mental illness, enhanced self-esteem and decision-making capacity, improved negotiation with clinicians increased compliance[17,51]. ADs have the potential to empower individual consumer's self-determination in decision-making, strengthening goals of consumer empowerment and "voice" in care; increase satisfaction, motivation, and treatment adherence for better, more cost-effective outcomes; enhance continuity of care, and promote early intervention and preventative care; encourage treatment collaboration and communication between the consumer, family, and clinical team about treatment options, preferences, and self-care; decrease reliance on coercive measures; assist in crisis de-escalation; and decrease hospitalization and costly court involvement[45].

Dr. Alok Sarin, in 2015[8] argued that "If this gives autonomy to the individual, it must necessarily be a good thing," or, "If it reduces the importance of the family in traditional societies, this cannot be a good thing for a society such as India." It is quite clear from the review of some experts who think that it is not worth as they contemplate on the possibility that India is not ready for ADs; others have said that they do not find any issues in ADs. Some professionals and service users may find them difficult to understand and fill. However, even though few difficulties may be reported in the proper implementation of ADs but it can be said for sure that if correctly implemented and executed then ADs offers many therapeutic benefits.

In short, it can be said that the stereotypes and stigma associated with mental disorders are frequently the main obstacles preventing early and successful treatment[52]. To understand these barriers, it is essential to look at what experts and research have to say about these concerns. It has come to light that nearly nine out of 10 people (87%) with mental health problems have been affected by stigma and discrimination[53]; that lead many people with severe mental illness to suffer manifold. They not only struggle with the disease-related symptoms and disabilities but also challenged by the stereotypes and prejudice about mental illness[54]; furthermore, lack of knowledge about the mental illnesses poses a challenge to the mental health care delivery system[55]; along with lack of trained mental health professionals. According to a Mental Health Survey carried out by the Directorate General of Health Services in 2002, there were only about 2,219 psychiatrists in the country, against the required 9,696; clinical psychologists were 343, against the desired 13,259; psycho-social workers available were only 290, against the required 19,064, while the number of psychiatric nurses was not available, though over 4,000 such trained nurses were required then. Also, while there were about 21,000 beds for mental health patients in the government sector, the number was just about 5,100 in the private sector[56]. As per an estimate, even if all 3000 psychiatrists available in the country are involved in face to face patient contact and treatment for 8 hours a day, five days a week, and see a single patient for a total of 15 - 30 minutes over a 12 months period, they would altogether provide care for about 10% - 20% of the total burden of severe mental disorders. Surprisingly, it is almost similar to the estimated 'treatment gap' of ninety percent[57]. On top, research has proved that mental health professionals often experience "compassion fatigue" because of the emotional labor that is often a part of therapeutic work[58,59] hence, it is important for them to deal with these negative aspects of cumbersome emotional work. Mushtaq & Margoob[60] stated that "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[60]. A large and growing concern is dealing with the burden or stress of caregiving that is experienced by almost 80% of people in the caregiving role[61], because of their burden or stress, and this can further complicate their situation. As per an estimate, there are about 10-15 thousand homeless persons with mental illness living only in Karnataka state[62] let alone the whole country. Unavailability or poor accessibility of the institutional care is making the situation more dreadful and remains the first step in facilitating recovery of homeless persons with mental illness[62]. It is also observed that individuals who have mental illness and their families are also vulnerable to face legal issues and the very nature of their illness may limit accessibility and effective utilization of legal services[63]. Mental Healthcare Rules, 2017 makes it clear that "all mental health establishments shall display signage board in a prominent place in local language regarding the right of the persons with mental illness to seek free legal aid and contact information of the Legal Service Authority"[56], it is to be remembered that Mental Healthcare Rules 2017 shall come into force on date of their publication in the Official Gazette and shall extend to the whole of India (Mental Healthcare Rules, 2017).

In short it can be said that potential problems associated with ADs include insufficient education of consumers about the role of ADs, how to complete them, and their limits; insufficient education of clinical staff and providers about ADs; concerns over requests for treatments not viewed as within the "standard of care" or best practices- seemingly one of the root causes behind the increased incidents of violence against medical professionals[41,42], or treatments that are not available in the community (or unaffordable); Lack of clarity around ability to carry out or revoke the ADs; uncertainty over who can/should be a health care agent, especially for individuals without available (or willing) family/friends; difficulty in predicting what treatment will be available and preferred in a "future" crisis; Stigmatizing to single out mental health consumers for distinct ADs, as somehow "different" from those with cognitive impairments completing general health care Advance Directives[45].

Insufficient attention to above mentioned logistical concerns may become significant barriers in the unbeaten implementation of ADs. Hence, it is the right time to use the wealth of information retrieved from case studies and research about the ways to overcome these obstacles and finding multiple ways to the successful implementation of ADs.

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