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Item Type	Article
Authors	Sarin, Alok;Murthy, Pratima;Chatterjee, Sudipto
Publisher	Forum for Medical Ethics Society
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Download date	2026-07-10 23:17:43
Link to Item	http://hdl.handle.net/20.500.12424/186249

Psychiatric advance directives: potential challenges in India

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Abstract

The advance directive is a statement of an individual's preference for future treatment. The concept initially evolved in the context of end-of-life treatment decision making. Subsequently, in some countries, advance directives have been promoted in the care and treatment of people with serious mental disorders. They have recently been endorsed by the United Nations Convention for the Rights of Persons with Disability. In India, the legal framework related to the care of persons with mental illness is currently being reappraised, and significant changes are being contemplated. Thus, this is an appropriate time to review the existing evidence on psychiatric advance directives and examine the potential challenges involved in making them legally binding.

A wide spectrum of mental health 'advance statements' have been developed and implemented in some high-resource countries. Of special interest to mental health contexts is the complex Ulysses contract to accommodate situations where the advance directive can be overridden during phases of acute illness or relapse. There have been mixed experiences with advance directives in the last couple of decades and there is scant evidence to suggest that they are effective in improving actual care.

There has been almost no discourse in India on the issue of mental health advance directives. Yet this feature is being considered for implementation in the revised legal framework for the care of persons with mental illness. There are significant barriers to the feasibility and acceptability of legally mandated advance directives. There are logistical barriers to operationalising them in a manner that guarantees quality assurance of the process, and minimises the possibility of misuse. Thus, while the advance directive is a highly desirable clinical tool for collaborative decision making between the person with mental illness and the treatment provider, at this time, more needs to be done before legal enforcement is considered in India.

Introduction

An advance directive is a mandate that specifies a person's preferences for treatment, should s/he lose the capacity to make treatment decisions in the future (1). The advance directive as a tool to maintain patient autonomy in treatment decision making has been most commonly used in end-of-life care settings (2). The use of the advance directive in psychiatric illness has a much more recent history, and has been in place, in some countries, for the last two decades (3). Mental health advance directives are intended to convey a

person's preferences for treatment in situations where s/he is not competent to do so in the future. Advance directives are a tool to promote the principles of participation and non-discrimination, and enhance mutual acceptability of treatment decisions as implicitly promoted in the United Nations Convention on the Rights of Persons with Disability (4).

In India, we are poised to enact different legislations to determine the care and treatment of persons with mental illness. The issue of advance directives is particularly topical since both the proposed legislations that will affect care provision for persons with mental illnesses - the Mental Health Care Act and the Rights of People with Disability Act - are potentially concerned with the concept of the advance directive.

Rationale for psychiatric advance directives

In spite of widespread perceptions that the mere presence of severe mental illness compromises decision-making abilities, the evidence clearly shows that for the majority of such persons, this is not the case (5). In this context, the psychiatric advance directive is often described as a significant advance that can empower persons with mental disorders to have a say in treatment decisions; in turn, this can help decrease coercion, increase treatment collaboration, motivation and adherence, and help avoid conflict over treatment and medical issues (6,7).

The psychiatric advance directive is interesting since it engages in a challenging conceptual interface -- the need to maintain the autonomy of the person with the need for appropriate treatment, in situations where there is disagreement between the parties involved. With the knowledge that many severe mental illnesses may be characterised by fluctuating mental capacity and loss of competence, the advance directive is an attempt to help the individual cope with the latter, without losing sight of the former.

History and international experience

In the wake of the Patient Self Determination Act, in the United States, mental health advocates appropriated some of the ideals of advance directives, and applied them to the context of patients of mental illness, who were seen to be particularly vulnerable to loss of autonomy and at risk of receiving unwanted interventions. These advocates hoped that the advance directive would give persons with severe mental illness greater autonomy and control over their own

lives; it would do so directly, during times of crisis, and perhaps indirectly, by improving continuity of care and improving the working alliance with mental health professionals, thus decreasing the need for involuntary treatment. It was also hoped that this would lead to a reduction of adversarial court proceedings (8-11).

A spectrum of advance statements has emerged in many developed countries (12). Apart from specific psychiatric advance directives, the spectrum has included

- ▶ facilitated advance directives,
- ▶ joint crisis plans,
- ▶ crisis cards,
- ▶ treatment plans, and
- ▶ wellness recovery action plans.

These vary in their goals, the level of involvement of the care provider, the role of the third party, the determination of competency, the nature of the advance agreement, and the degree to which they are legally binding (12). The debate on advance directives in mental health has resulted in legislative reform in some cases (New Zealand, UK, Scotland, Canada and the US). In Germany, Austria and Switzerland, advance agreements (*Behandlungsvereinbarungen*, which translates as "treatment agreements") are routinely offered in many hospitals, according to a web search in 2008 (12). Common features of these agreements are: requests for treatment in a particular hospital or ward; requests for treatments that were helpful in the past, or directives about those that should not be used; preferences for staff gender and emergency measures (forced medication versus physical restraint); nomination of the person to be consulted on decisions about treatment; and arrangements for dependents during hospital treatment. *Behandlungsvereinbarungen* are seen as legally binding, but it is acknowledged that a service user's wishes at the time of hospital treatment would normally override a previous agreement.

However, there have been various differences across countries. These differences are in: the definition of advance directives, variations in terminology, determination of competence to make such a directive, mechanisms for making a directive, the legal status of such directives, whether the wishes of the person being treated at the time of admission override any earlier advance directive made by the same person, and the time validity of the advance directive.

In the new statutes in some US states, clinicians are not required to follow directives that conflict with community practice standards, or with the need for emergency care, or that are unfeasible, or if the patient meets involuntary commitment criteria (12). Similarly, advance statements can also be overridden in the UK. In Australia, the utility of advance directives has been questioned; it is felt that they have failed to guide clinical decision making. Of particular concern is the dilemma facing clinicians when the advance directive rules out treatment which the doctor believes is in the patient's best interests. Currently in Australia, mental health legislation

can override an advance directive (13). In the state of New York, an attempt to harmonise psychiatric advance directives and involuntary commitment is the Kendra's Law which states that when a person subject to court-ordered treatment has a health care proxy, any advance instructions given to the proxy must be considered by the court in determining the written treatment plan (14).

The Ulysses contract

Depending on the lens which one uses to view mental illness, it is often felt that patients of mental illness have two different 'selves'. One self acts on the urging of short-term impulse, mood or emotion, as evidenced by the manic episode in bipolar disorder, where the individual may start manifesting unusual assertiveness, grandiosity, irritability, impulsivity, and risk taking behaviour. The other 'self', when out of the episode, may actually rue the behaviour during the 'manic' episode, because such behaviour may be detrimental to personal safety, financial security or interpersonal relationships.

The solution offered to this difficulty is the 'Ulysses contract' or the 'Odysseus pact' (15, 16). As the proponents of the voluntary commitment contract put it, "Just as [Ulysses] instructed his crew to bind him to the mast before they sailed past the irresistible Sirens and to ignore his requests for release, such patients should be able to contract with their physicians to disregard certain specified instructions they might issue during relapse (such as refusing needed treatment) for a limited period of time."

Thus, by providing, in advance, consent to treatment and waiving the right to refusal, the Ulysses contract puts in place a process that introduces concepts of pre-commitment, self binding and self paternalism (17).

However, as pointed out by Dresser, as it moves from "literature to law" it is important to note that Ulysses' clever directions to his crew were based on his knowledge of what hearing the song of the sirens could do. He was also acting as the captain and sole arbiter of authority of the ship, and the 'contract' was only between the crew and himself, without any third party. In operational terms, when it becomes legislated policy, the state, which becomes the enforcing party, then has to determine when the party to be restrained has lost the power of self-control, and has to predict the consequences of such loss. Furthermore, the power of the state must be invoked to enforce the legally binding agreement (17).

"Unpacking" the concept

While in many ways, the rationale for the advance directive seems self-evident, when we delve deeper, a number of issues emerge.

The use of Ulysses contracts raises a number of ethical concerns, including the questions of moral authority, personal identity, revocation during crisis and the risk of misuse and abuse. It is unclear as to how the process ensures that using advance directives is a process not enforced upon the patient.

An example cited is whether a patient who does not sign a contract can be refused treatment (18).

Elaborating on these concerns, Widdershoven and Berghmans stress the need for looking at the advance directive as an ongoing communication between the patient and the doctor in a narrative context. They suggest that when the advance directive is used in a clinical setting, the moral authority comes from the fact that it stems from a reflection of the patient's wishes. It goes beyond merely recording instructions to the treating team; it becomes a record of the ongoing, informed discussion regarding treatment modalities between the patient and the doctor. It is then to be viewed as a tool, not to replace discussion, but to facilitate ongoing communication.

It has been argued that advance authorisation for future psychiatric care can only be valid if this expresses values which are crucial to the patient's life. Feinberg argues that the voluntariness of a decision is the decisive criterion. Another approach is the so-called "cool moment" theory (19). Whether a wish is authoritative is connected to the individual's stated preferences in the "cool moment": i.e. the moment at which the person who has conflicting preferences is neither in the grasp of one desire or the other. Typical examples are an alcoholic who is considering quitting drinking and a patient suffering from bipolar disorder.

Effectiveness, feasibility and uptake

However, despite the fact that advance directives have been in place for some time, the evidence of their effectiveness is very limited. There has, actually, been little in the way of research into the effects of advance directives in promoting the objectives of informed choice and consensual treatment during episodes of acute care. There is more data on their effects on health service use, but even here the results have been equivocal (20, 21). Some of the disparities in results may be due to differences in the sample including selection bias, or in the type of intervention (22). More intense interventions, including a lengthy interview with patients and their carers (21), appear to be more effective than providing patients with a booklet for completion (20). In a recent exhaustive Cochrane review of advance directives, the authors conclude with the comment: "Currently it is not possible to recommend advance treatment directives for people with severe mental illness due to the lack of supporting data." (1) This highlights the need for further research to validate the concept.

The main opposition to advance psychiatric directives has been that they are undesirable and unworkable in practice; giving mentally ill persons the right to consent to or refuse mental health treatment before the onset of any psychiatric illness does not actually promote or protect their best interests, since future decisions cannot be made about potentially unforeseen circumstances (23). Others view it as leading to legal and ethical problems, and being unworkable (24, 25).

Other concerns about advance directives include situations where patients may agree to some treatments in their advance

directives, but not others, even when they may be more appropriate for the patient (26). One solution is to involve third parties in the agreement (21). Although this may be associated with better outcomes in terms of health service use, it may add to their complexity and undermine the very autonomy that advance directives are designed to protect (26). Another problem concerns the issue of who should decide whether a patient is actually competent when s/he formulates an advance directive - the treating physician or the courts (26). A related issue is the patient's cognitive and mental state when making an advance directive. Competence relies on an individual's ability to process, evaluate and apply information. However, the individual's ability may be compromised by various factors. For example, feelings of hopelessness secondary to depression may lead individuals to underestimate the effectiveness of available treatments. Solutions include careful documentation of competence at the time of the directive, or the addition of a rider stating that in the event of incompetence, the patient's proxy would be mandated to override those treatment decisions that are judged to be not in the patient's best interests.

Informing the discourse in India

The issue of the use of advance directives in psychiatry has not received much attention in academic or social fora in India till date. The question of the applicability and effectiveness of psychiatric advance directives in India is certainly relevant, especially since the current evidence for both effectiveness and usage seems, somewhat surprisingly, to be marginal in countries where this has been implemented.

Challenges related to service delivery methods

The diversity of the various forms of psychiatric advance directives is an indicator of the critical influence of the particular social, political and service delivery contexts where they have been operationalised, as also the fact that different societies are trying to negotiate differently with this complex concept. All of these are very different in India, especially the service context. Advance directives implicitly work within an accessible, well defined and predictable service delivery context. The relatively unorganised nature of services in India, and the limited access to them, makes the use of advance directives particularly challenging.

Abuse and decision making related challenges

The other concern that has been raised is of the possibility of abuse and misuse of this tool. In countries and societies where monitoring and regulatory controls tend to be either lax or non-existent, the possibility of the misuse of this tool is very real. Again, in the Indian context, the involvement of family members in determining the type and requirements for acute care is critical. Any plans for the introduction of advance directives needs to take into account the views and preferences of key caregivers as well. Otherwise, it runs the risk of alienating users, families and care providers, rather than encouraging collaboration between the parties.

Challenges related to the creation of supporting agencies

Another issue of concern is the requirement for dedicated resources (like competent legal aid services) for the implementation of advance directives in an accessible and affordable manner. In addition, local complaints and dispute redressal agencies to manage conflict arising out of the implementation of the advance directive, and an ombudsman-like agency at each district level, will be needed. This is an issue of concern in India where such resources are sparse in rural settings and for a large proportion of vulnerable population groups. Otherwise, there is a possibility of the use of advance directives being restricted to urban elites who have access to services, information and resources to execute them. Finally, effective monitoring systems, that will capture the process, uptake and utility of advance directives in the acute care context, are needed. This is a significant challenge that requires considerable financial and human resources which is a potential barrier in India.

We believe that, given these challenges, the adaptation of advance directives in the Indian context needs to be researched in detail around the issues of feasibility, acceptability to a range of primary and secondary stakeholders, and effectiveness in implementation. This process will allow for the identification of the logistical, ethical, legal and operational barriers that need to be addressed before legal adoption can be advocated.

Conclusions

The advance directive is a mechanism for involving and empowering persons with mental illnesses in taking charge of their lives and participating in clinical decision making. The authors are of the opinion that the use of the advance directive as a clinical tool, embedded in the nature of the clinical narrative, is certainly something which should help in both facilitating and nurturing dialogue. It can thus potentially serve as a clinical tool for collaborative decision-making. However, the utility of such a directive as a legal tool seems fraught with complexities in conceptualisation, operationalisation and application. At present, it is not supported by adequate evidence of its utility. Further debate and discussion are needed before the advance directive can be incorporated into the legal provisions that will govern the care of persons with mental illnesses in India in the near future.

Acknowledgements: The Nehru Memorial Museum and Library, Teen Murti House, provided funding support for a workshop titled "On living wills and Ulysses clauses, the use of advance directives in psychiatric practice organised on February 23, 2011, as part of the fellowship programme of Alok Sarin. The contribution of all the participants is gratefully acknowledged.

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