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Advance Will: Ensuring the Right to Autonomy for People with Mental Disabilities

Abstract. People with chronic mental illnesses (e.g. bipolar disorder, schizophrenia, dementia, etc.) find it hard to maintain normal and independent everyday life. Due to these illnesses, people usually lose competence to make autonomous decisions about their treatment. However, in some cases those people are still competent to make reasonable decisions before the times of relapse or at the early stage of disease. As a possible solution, some jurisdictions offer instruments to express a patient's will in advance (e. g. advance directives), where mentally ill patients may state their treatment and care preferences for the future time of incompetency. Although there is a lot of criticism presented by the scholars, legal instruments based on advance will may undoubtedly contribute to ensuring mentally disabled patients' fundamental rights and quality of life. Therefore, this article will include an introduction of advance directives, the advantages this tool represents and discuss main regulation challenges.

Keywords: advance will; advance directives; right to autonomy; mental illness; mental disability; mental health; mental health care

Introduction

Approaching and administering mental disability² caused by chronic mental illness (such as bipolar disorder, schizophrenia, dementia, etc.) is still one of the

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2 Also, it may be referred to as psychiatric disability, mental disorder, mental impairment, mental illness, etc.

most difficult and widespread issues in modern society. The extent of mental health problems is a growing public health concern as numbers of affected people are extremely high. According to World Health Association (WHO), about 264 million people globally have depression, 45 million – bipolar disorder, 20 million – schizophrenia or other form of psychoses, 50 million – dementia (World Health Organization, 2019). Actually, depression is considered to be one of the leading causes of years lived with disability worldwide, and in many countries is held to be the primary driver of disability (Mental Health Foundation, 2016). As the number of mental illnesses continues to grow, not only does it cause suffering for individuals and their families, it also has a strong impact on overall society and economy, and it raises significant concerns on protection of human rights.

To lead a normal and productive life for the people affected by chronic mental illness is a permanent challenge. Adaptation to different and recurrent symptoms of the illness is the main struggle not only for the individual but also for his relatives, friends and colleagues. A lack of insight into their actual condition usually prevents those people from applying for treatment or following the prescribed one. This is the main reason for disease progression, which can cause that person's condition to a severe relapse. Nevertheless, there are cases where those people do not meet the legal criteria for involuntary treatment, and they retain full right to refuse to be treated (Dunlap, 2000). Consequently, a person's mental health deterioration predetermines coercive treatment assuming that person's behaviour might be dangerous to himself or others.

Mental illness itself is just one part of the challenge that an individual has to learn to cope with. The prevalent misconceptions of mental disabilities determine various stereotypes against people with mental illness. Firm and entrenched stigma deprives mentally ill individuals of an opportunity to receive equal treatment and care approaches. Stigmatizing views about mental disability are endorsed not only by the general public but also among well-trained professionals from most mental health disciplines (Corrigan & Watson, 2002). To be more precise, while the patient is still competent to make reasonable and autonomous decisions regarding his treatment and care preferences, he is generally unable and not allowed to participate in the decision-making process. This is caused by dominant prejudice that individuals with severe mental illness are not responsible enough to make decisions about their lives on their own (Corrigan & Watson, 2002). For this reason, mentally ill people are not considered as reasonable and competent enough to make a sound decision when in fact at times (e.g. during a recess period or at the early stage of disease) they retain full competency. Not having a position to experience a true sense of their own will and choice during course of treatment pre-empts a patients' right to autonomy, which is actually recognized as the human right protected by The Human Rights Act (Samanta & Samanta, 2005).

This article presents Mental Health Advance Directives³ (MHADs⁴) as a possible solution for the previously presented issue. This legal tool is adopted in some jurisdictions⁵ as a possibility for mentally ill patients to state their treatment and care preferences at a future time of incompetency. This document allows the person to make decisions regarding his treatment in advance, while he is still competent. These would come into force during the periods of poor mental health condition when the person would be unable or incompetent to make a sound decision. Hence, the MHAD comes into force only when the patient becomes incompetent (Dunlap, 2000). However, for many years now MHADs have been debated. Evidently, there are number of supporters who stress the importance of MHADs as well as a much criticism against this legal instrument.

The concept of MHADs

To form a proper understanding of the benefits and weaknesses of MHADs it is essential to analyse the concept of this legal instrument. Needless to say, that MHADs are a quite popular topic among academics and even practitioners. There are number of scholarly publications introducing MHADs definition and debating various aspects of their efficacy, yet they all demonstrate the lack of systematic approach. Nevertheless, *prima facie* review enables the most relevant elements of MHADs to be distinguished and determined

To begin with, it is worth mentioning that MHADs are a relatively novel concept as MHADs were introduced in 1980s (Swanson, McCrary, Swartz, Elbogen, & Van Dorn, 2006), and, for example, in Lithuania, they have not been particularly prevalent and common up to now. One of the first scholars and probably one of the most active ones in this field is Paul S. Appelbaum, who perceived an MHAD as a document, which "... written while a person is competent, specifies how decisions about treatment should be made if the person becomes incompetent" (Appelbaum, 1991). To elaborate this idea, MHADs allow people to specify not only how decisions about their treatment should be made but also to set forth those decisions and their content. To be more precise, MHADs may consist of instructions regarding the use of medication, specific treatment approaches, alternatives to hospitalization, experimental treatments, methods for handling emergencies, preferences for particular hospitals, emergency contacts, and people who will be allowed to visit, as well as people who will be responsible for child care, finances, etc. (Srebnik & La

3 Also known as Psychiatric Advance Directives (PADs), Advance Statements, Advance Directives, etc. While a variety of definitions have been suggested, this paper will use the definition of Mental Health Advance Directives.

4 Throughout this article, the term MHADs will refer to Mental Health Advance Directives.

5 For example: United States, Germany, Netherlands, Belgium, etc.

Fond, 1999). In addition to this, MHADs may include patient's treatment history, medical side effects (Wilder, Elbogen, Swartz, Swanson, & Van Dorn, 2007) and other relevant information useful for a physician in emergency situations. Actually, the patient may base his future treatment preferences on his prior experiences of relapse, allowing him to choose what works best for him (Brodoff, 2010).

It is worth emphasizing that MHADs are particularly relevant for "... the patients who experience recurrent cyclical and progressive incompetence during episodic crises as a result of their mental illness" (Žalčiauskaitė, 2015) because those patients experience both periods of competency and incompetency. During the periods of competency or at the early stage of the mental illness, a patient may form an MHAD and adjust it after periods of incompetency if needed. This represents the paramount importance of MHADs for people with a mental disability since MHADs enhance decisional autonomy and the self-determination of the person assuming that the treatment will be provided as was agreed in advance (Elbogen et al., 2006; Gooding, 2013; Wilder et al., 2007) little is known about clinicians' understanding and perceptions of these legal tools. Methods: A total of 597 mental health professionals (psychiatrists, psychologists, and social workers. This also means that, the "MHADs model suggests shifting the sole decision-making from the doctor to create a therapeutic alliance between clinicians and the patient by involving the latter in the treatment selection process" (Žalčiauskaitė, 2015). In other words, MHADs ensure the right to autonomy for the patient as long as the patient's opinion, wishes and preferences are heard and respected. In fact, this decisional alliance supports the idea that "... the clinician and the patient collaborate together to reach an agreement regarding the understanding of the problem and the most appropriate treatment" (Khazaal, Chatton, Pasandin, Zullino, & Preisig, 2009). Meaningful involvement and shared decision-making provide the chance for mentally disabled people to retain some elements of independence, thus assigning considerable value to the use MHADs.

To sum up, there are no commonly accepted definition of MHADs and varying interpretations of different aspects of MHADs predominate throughout the scientific sources. However, comprehensive and plentiful international scientific literature concerning MHADs has established an initial and plain understanding of this concept.

Supporting attitudes towards of MHADs

Part of academic society recognizes the significant benefits of MHADs and emphasizes MHADs fundamentality and importance. Considering the previous section's concept, it is evident that MHADs may contribute to the improvement of mental health systems as well as to the protection of basic human rights, especially

safeguarding the right to autonomy. There are a number of virtues that MHADs represent though this section introduces just the main and fundamental ones.

The pivotal argument that most of the scholars base their support for MHADs is that MHADs enhance patient autonomy (Khazaal et al., 2009; La Fond & Srebnik, 2002; Nicaise, Lorant, & Dubois, 2013). As previously mentioned, MHADs ensure a patient's involvement in the decision-making process, giving him voice and respect, which he usually loses due to prevailing stigmatization. This argument is directly connected to the basic human rights' protection, which is another reason of why MHADs receive that much support. Indeed, even the Convention on the Rights of Persons with Disabilities promotes the "[r]espect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" (United Nations, 2008). In the context of MHADs, this pivotal principle of the Convention recognizes and safeguards the right to autonomy for mentally disabled people, while highlighting the importance to provide them full equality under the law. It is important to mention that Convention has inspired substantial international attention towards the improving the acceptance and recognition of MHADs (Sellars et al., 2017) whereas the clinical profile of and risk to the patient and the professional or ethical imperative of the psychiatrist were strongest among those who were unsure about supporting the patient or who did not support the patient. These findings provide a challenge about how to fulfil obligations under the United Nations Convention on the Rights of Persons with Disabilities (2006).

As a matter of fact, research suggests that usage of MHADs could generate a positive therapeutic impact on patient's treatment results as, firstly, the patient would feel heard, trusted and in control on his treatment, and secondly, he would be more motivated and invested in treatment and surrender to it more easily believing that this is his own choice (La Fond & Srebnik, 2002). MHADs are also very therapeutically beneficial if the patient determines early treatment and establishes conditions and means to follow it. Namely, despite the chronic and long-term nature of mental disability, a patient may live a fulfilling life with the proper treatment; to illustrate this, "[o]ver 80 % of people with schizophrenia may be free of relapses at the end of one year of treatment with antipsychotic drugs combined with family intervention" (World Health Organization, 2001). Furthermore, some scholars believe that MHADs *per se* are rather therapeutic (Backlar, 2004) as it might be an integral part of a patient's recovery through increased autonomy and empowerment (Srebnik, 2004). From another perspective, it is believed that the most harm is done to persons with disabilities when their legal capacity is not respected and/or denied (Burch, 2017). Actually, developing therapeutic alliance based on respect, collaboration and autonomy might increase both trust in a physician and trust in a treatment, resulting in patient's positive attitude, social satisfaction, personal control of his well-being, voluntarily and responsibly following the prescribed treatment. In addition, a positive therapeutic alliance is considered to have significant emotional

support (Pinto et al., 2012), especially to those patients having no assistance from their family or friends.

Considering the positive therapeutic outcomes, the other relevant benefit of MHADs is minimizing the use of coercive practices. In fact, overuse of coercion in mental health care is a rather longstanding problem as a variety of international reports reveal violence, abuse and aggression towards mentally disabled individuals (Duxbury, 2015). These negative experiences not only reduce the quality of life for persons with mental disabilities but might also generate negative therapeutic outcomes. Moreover, the fear of coercion may even keep a mentally ill person away from seeking help and treatment (Gooding, Mcsherry, Roper, & Grey, 2018). Conversely, a study of MHADs completers (n=147) and non-completers (n=92), conducted by Swanson and his colleagues, revealed that MHADs "... may be an effective tool for reducing coercive interventions around incapacitating mental health crises" whereas "[l]ess coercion should lead to greater autonomy and self-determination" (Swanson et al., 2008). Indeed, there is an essential need to change the paradigm from paternalistic views and fear towards mentally disabled people to greater focus on fostering patient-centred, collaborative approaches. Therefore, MHADs might be an effective solution to reduce the usage of force as the patient would most likely commit himself voluntarily under the belief that he is implementing his own previously stated wishes (Žalčiauskaitė, 2015). It is also believed that the MHADs formation process itself as a self-management technique might also reduce negative pressures of coercion by mitigating anxiety "about the treatment should future crisis occur" (Backlar, 2004). In addition to this, MHADs grant the possibility to ensure early intervention which helps patient to avoid involuntary commitment (Clausen, 2015; Winick, 1996). Overall, it seems that MHADs create additional positive therapeutic impact as much as reduce the negative factors that exist in general mental health care.

Creating the possibility to decide and avoid coercion, MHADs also provide an opportunity to choose alternatives to psychiatric hospitalization. Primarily, this is a question of economic costs; on the one hand, it reduces costs for the state to maintain traditional public hospitalization care; on the other hand, it reduces the overload of psychiatric facilities. Moreover, there are alternative facilities that offer the same or even better quality and more optional services (e.g. nursing homes, hospices, home care services, etc.); therefore, the ability to choose them over traditional psychiatric wards may foster and support their business growth (Žalčiauskaitė, 2015). The support and encouragement for the patient to choose alternatives to hospitalization promotes the patient's right to autonomy, enabling the patient to make his own decisions that would make him feel comfortable and safe when implemented.

Lastly, MHADs might solve at least part of the problem regarding untreated patients. According to the statistics, about 40-60 % people with severe mental disorders receive no treatment at all (Ellis, 2019). For example, in Lithuania,

a hospital does not have the right to implement treatment without the patient's consent if the patient does not meet involuntary hospitalization criteria and refuses treatment (Law on Mental Health Care of the Republic of Lithuania, 2019). The initial symptoms of mental illness might influence an untreated individual to make rather irrational and harmful decisions (one of which may be refusing treatment) hereby negatively affecting his and his family's quality of life (e.g. losing a job, becoming homeless, etc.) (Saks, 2004). It is worth mentioning that untreated mental illness most commonly (about 90% of the time) leads to suicide (Brådvik, 2018). These numbers signal the essential need to find effective ways to de-escalate this problem and provide legal tools to help individuals seek help. With that said, it appears that by stating treatment obligations in advance, MHADs may reduce the amount of untreated individuals and provide the necessary treatment at the early stage of disease or relapse.

To summarize, as a legal tool MHADs represent rather significant benefits for mentally disabled individuals, their family, and the overall mental health care system. Taking into consideration the possible positive outcomes of MHADs usage, more attention should be given to clarification of the MHADs concept, seeking effective regulation and international unification of this legal instrument.

Criticism of MHADs

Despite the importance prescribed to MHADs, there are many scholars who express criticism of MHADs, emphasizing their weaknesses and unresolved issues. This section provides the most common counter-arguments against MHADs.

To begin with, one of the main concern regarding MHADs is focused on patient's autonomy, such as conflict of interests regarding 1) others; 2) patient's own interests; and 3) Ulysses provision⁶ (Žaliauskaitė, 2015). Firstly, scholars have made the observation that “[t]he potential for conflict between interests of patients and those of others, including the safety interests of the general public, highlights a key weakness inherent in PADS” (Swanson et al., 2006). In other words, scholars express concerns that MHADs might create certain situations where the interests of mentally disabled individuals may be put above others. By way of example, a patient might put an economic burden on society by refusing intense treatment *ipso facto* increasing the length of hospitalization (Srebnik & La Fond, 1999) or imposing a financial burden on family members by choosing expensive treatment (Ritchie, Sklar, & Steiner, 1998). These illustrations draw attention to the content of MHADs indicating the need to set limits on the decisional freedom of an individual creating an MHAD. With regards to a patient's own interests, it is argued that the

6 Ulysses provision in MHADs is a certain provision validating contract irrevocability.

patient's right to autonomy is not the principal one compared to other rights and values. For a long time, the courts of United States of America deemed that "... while individual autonomy may be the primary value in principle, other values, such as the sanctity of (worthwhile) life and the patient's welfare, will outweigh it in practice" (Federal Patient Self-Determination Act, 1995). In fact, this argument against MHADs is based on the concern that an individual may state certain conditions in his MHAD that would preclude a physician from implementing vital treatment putting the patient's life at high risk or even causing death (passive euthanasia). This is also a question of regulation: which one has a priority – the Hippocratic Oath and the person's life or the MHAD and the person's right to autonomy? These are quite difficult questions which still have no overall unified agreement. Lastly, the Ulysses provision causes a contradiction "when the patient's wishes stated in MHAD contravene the present wishes during implementation of MHAD" (Žalčiauskaitė, 2015). The question of which volition is "true" and should prevail places the physician in a complicated ethical dilemma (Swartz, Swanson, & Elbogen, 2004). Nevertheless, this argument appears to be minor one as this might be solved by providing regulations and guidelines on competent volition determination and compliance. However, the question of patient's competency in another question of debate as there is no general single method to determine it. Having an objective evaluation of a person's competency is not only important in the MHADs formation process but also in the situations when MHADs should begin to be executed. Nevertheless, taking into account that people have different personalities and different mental illness experiences, scholars hardly find common grounds for the determination of competency thus leaving the evaluation process for physician's subjective judgments (Backlar, 2004). Additional research is needed in order to ascertain whether that kind of approach is effective enough.

Another criticism revolves around the lack of knowledge and understanding of MHADs, doubts on person's ability to complete an MHAD, MHAD clearness, MHADs availability during crises and distrust in physicians (Žalčiauskaitė, 2015). Firstly, research suggests that both patients and health professionals lack particular knowledge and understanding about MHADs and guidance on their implementation (House & Lach, 2014). Again, more attention should be concentrated on the regulation of MHADs focusing also on the readability and clarity of the laws. Besides this, professional training programs and additional consultations must be provided for medical staff. Secondly, it is believed that supposedly the patient may not be able to properly understand his preferences (Mahon, 2011) due to the lack of knowledge, experience or even medical education. This could become a complicated situation "... during the MHAD implementation process when the patient realizes that the course of treatment is not what he expected" (Žalčiauskaitė, 2015). On the other hand, the clearness of the MHAD for the physician is also a question of debate. In particular, the discussion is pursued on how detailed MHAD should be to

minimize the risk of misuse and misinterpretation while also not being cumbersome and difficult to implement (Swartz et al., 2004). Finally, MHADs might not be available during the crises due to patient's incompetence to state the existence of the MHADs or to different emergency settings (e.g. during travels) (Swartz et al., 2004). Yet, this is a matter of collaboration among mental health care systems of different countries and effective and approachable tools (e.g. online platforms, data clouds, etc.) to make MHADs available for other hospitals personnel.

In conclusion, it is apparent that there are certain major weaknesses of MHADs that need to be considered and addressed. Mostly, the criticism involves a variety of implementation aspects stipulating the necessity to reconsider and adjust regulation of MHADs. Bearing in mind the significant benefits of MHADs, legislators, politicians and society in general should pay more attention to this legal instrument to foster, promote and strengthen the utility of MHADs.

Final remarks

Despite the fact that there is a significant amount of attention paid to human rights protection internationally, mentally disabled people still remain one of the most exposed and unprotected parts of society. This article has presented Mental Health Advance Directives as a legal tool for mentally disabled individuals to have an ability to implement their decisional autonomy regarding their treatment and care. Regardless of the criticism expressed by a variety of scholars, MHADs have a strong potential to improve the quality of life of mentally disabled individuals and their families thereby upgrading mental health care system.

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