Protecting the Autonomy of Patients with Severe Mental Illness Through Psychiatric Advance Directive Peer-Facilitation

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ABSTRACT

Psychiatric Advance Directives (PADs) can protect the autonomy of those living with severe mental illness (SMI) and improve their treatment outcomes. However, their uptake is low for several documented reasons. Attempts to increase patient uptake of PADs can circumvent risks of undue provider influence in the facilitation process and promote optimal mental health outcomes with a peer-support model, thereby protecting patient autonomy in accordance with the principle of beneficence. Moreover, policymakers and mental health organizations should devote sufficient resources toward establishing peer-support specialist networks to mitigate the inequities those with SMI face. Capability theory can guide state leaders and directors in justifying the distribution of scarce resources to achieve these outcomes.

Keywords: Psychiatric Advance Directives, Autonomy, Severe Mental Illness, Involuntary Commitment

INTRODUCTION

Since the mid-twentieth century, scholars have increasingly rejected a strong paternalistic relationship between physician and patient, emphasizing the right of patients to accept or decline medical treatment.[1] With this greater emphasis on patient autonomy, a healthcare model of shared decision-making ascended in the 1980s.[2] Considering limitations in a patient's capacity to make informed decisions in their treatment, the US Congress passed the Patient Self-Determination Act in 1990.[3] The act legally obliged hospitals and other care facilities that participate in Medicare and Medicaid to ask patients if they have an advance directive. In the absence of such a directive, these institutions are to ask if patients would like to complete one and to abide by it if presented by the patient.[4]

These directives give patients control of future medical decisions in three key areas: entrusting an individual to act as a medical decision-making proxy, preferences for and consent to future treatment, and a statement of overall personal values and preferences to help inform future medical decisions by providers.[5]

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Although professionals initially crafted the law with end-of-life care in mind, 27 states now have mental health-specific provisions included in advance directive statutes.[6] As a subset of advance directives, psychiatric advance directives (PADs) are meant to protect patient autonomy during the treatment of psychiatric episodes when competence is compromised. Despite their promise and protection, PADs are underutilized by those with serious mental illness (SMI).

In a survey of psychiatric patients, only 4-13 percent of respondents across multiple US sites reported having completed a PAD.[7] The same study indicated that 66-77 percent of respondents were interested in completing one if given assistance.[8] Having recognized the gap between patient interest and uptake, researchers have explored the possible reasons for this disparity. Several barriers have been identified and characterized at the system, health-professional, and service-user levels.[9] Although exploring interventions targeted at each level individually may be worthwhile, several barriers may be effectively overcome with one cross-level intervention. Specifically, a network of peer-support facilitators may be able to mitigate resource concerns of the system level, provider fears, reluctance, and lack of knowledge of PADs at the health-professional level, and a lack of trust and support among those with SMI within the service-user level.[10]

Although the Patient Self-Determination Act mandated protections for patient autonomy, the law did not provide a sufficient mechanism to ensure the broad use of those protections. Much of the logistical burden falls on those living with SMI to educate themselves and initiate the completion of a PAD.[11] However, many of those living with SMI already face additional burdens that prevent their successful navigation of a complex healthcare system, including poverty, marginal housing, and food insecurity.[12] In addition, individuals with SMI tend to be more socially isolated, with few others to trust besides their providers.[13] Efforts to promote the uptake of PADs by those living with SMI that neglect these additional burdens risk exacerbating health inequities faced by those with SMI.

Attempts to increase patient uptake of PADs should circumvent risks of undue provider influence in the facilitation process and promote optimal mental health outcomes with a peer-support model, thereby protecting patient autonomy per the principle of beneficence. Additionally, policymakers and mental health organizations should devote sufficient resources toward establishing peer-support specialist networks to mitigate the inequities those with SMI face. Capability theory can guide state leaders and directors in justifying the distribution of scarce resources to achieve these outcomes.

I. System-Level Barriers to Psychiatric Advanced Directive Uptake

At least three barriers to PAD uptake exist at the system level. Still, only one can be effectively addressed by peer-support specialists: resource implications to providers and administrators.[14] In one study, 71 percent of administrators and 52 percent of clinicians believed that a shortage of time would prevent adequate facilitation of PAD completion among those with SMI.[15] Logistical difficulties, such as incorporation into routine documentation and making them easily accessible, were mentioned by 25 percent of respondents in another study.[16] Professionals should take clinical burdens seriously since they can impact care and patient outcomes. Shifting to a peer-support model would alleviate these constraints on providers, who could then focus on other aspects of patient care.

II. Health Professional-Level Barriers to Psychiatric Advance Directive Uptake

Barriers at the health-professional level, which include a lack of knowledge and training, fear of complete treatment refusals, and a reluctance to facilitate PAD creation, keep patient uptake of PADs low.[17] Among these barriers is a need for more knowledge and training among healthcare professionals. In one study, 55 percent of health professionals had never heard of PADs; only 11 percent claimed they were "very familiar" with PADs.[18] In a survey of professionals, 45 percent voiced concern that the potential disadvantages such as the use of PADs to refuse medications could outweigh the benefits.[19] The reluctance of providers to assist service users in completing a PAD stemmed from concerns over time constraints and the providers' ability to facilitate the completion of a PAD without bias.[20] These concerns are serious and hint at the asymmetrical power dynamic between providers and patients. By removing the responsibility of unbiased communication from the provider and placing it with peer-support facilitators, the risk to patient autonomy would be significantly lessened.

III. Service User-Level Barriers to Psychiatric Advance Directive Uptake

Several barriers exist at the service-user level that prevent the widespread adoption of PADs. These include a lack of trust, support, and knowledge of PADs, as well as a lack of understanding in completing a PAD.[21] Concerning trust, one study found that 43 percent of patients did not feel they had someone they could trust to help them complete their PAD.[22] Other studies indicated that patients had limited trust in their healthcare professionals.[23] Regarding the lack of support, one survey found that 94 percent of respondents would be unable to complete a PAD without assistance or without a facilitator.[24] Many patients lack knowledge and awareness of PADs, how to complete, and what to include in them.[25] Due to their complex legal nature, over half of the respondents in one survey indicated that they had problems understanding the PAD.[26] Similarly, 79 percent of clients interviewed in one study felt that PADs posed too much of a burden.[27] Through their shared lived experience, peer-support facilitators would be in a greater position to foster trust with patients and create the environment necessary for patients to explore their values and preferences through this process.

IV. Circumventing Undue Provider Influence on Patient Autonomy

The risk to patient autonomy is pervasive because of the advanced nature of medical practice and the dependence of patients to providers. In their delineation of bioethical principles, Beauchamp and Childress state: "To respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their values and beliefs."[28] This duty extends through a respectful *attitude* toward the patient and respectful *action* toward the patient.[29] On average, patients with SMI take 14.6 minutes to complete a PAD, which is well within the 30-minute time limit imposed by insurance reimbursement schedules.[30] However, as other researchers have indicated, this time of completion does not take into account the time required to inform and discuss the implications of future treatment decisions adequately.[31] Given that those living with SMI are often affected by cognitive deficits, the ability of a provider to relay complex health and legal information promptly may be further hamstrung.[32] By offloading the burden of providing efficient and practical education to patients with various levels of cognitive impairment, peer-support specialists could provide the necessary space and time to obtain informed consent and protect patient autonomy.

Much of the moral force behind advance directives is the respect for patient autonomy, which has been a focus of researchers over the past several years.[33] Because psychiatric episodes severely limit the ability of a patient to make well-informed treatment decisions in a crisis, PADs are a way to protect the patient from paternalistic interventions. This takes on greater weight in treating patients experiencing a psychiatric episode when the threat and use of coercive treatment options are frequent.[34] Moreover, a report in North Carolina has uncovered a "culture of commitment" whereby providers routinely and reflexively override patient PADs through the legal execution of involuntary commitment.[35] This is despite the affirmation of the autonomy of psychiatric patients by the US District Court in Vermont, which concluded in *Hargrave v. Vermont* that clinicians could not overrule written directives regarding mental health treatment in non-emergency situations.[36] Although the invalidation of a PAD occurs during treatment, well after discussing and creating it, providers holding the view that PADs are of little utility may not accurately or effectively discuss their relevant features with patients. However, this issue could be side-stepped entirely with peer-support specialists who would be responsible for obtaining informed consent from the patient within the value structures espoused by the patient.

V. Beneficence Through Peer Support

A growing amount of research indicates how peer-support facilitation of PADs can improve the mental health outcomes of those with SMI. Studies show that adults with SMI can complete legally valid PADs with appropriate assistance and that these documents faithfully represent their preferences.[37] At a minimum, service users report no bias against peer specialists in facilitating PADs.[38] Peer-support specialists use their lived experience to foster empowerment among patients, serve as role models, and promote a patient-centered process in successful PAD completion.[39] Mitigating concerns from providers that PAD creation would include complete refusal of treatment, other studies have found that peer-facilitated PADs were significantly more likely to be prescriptive than PADs facilitated by non-peer clinicians.[40] Most importantly, peer-facilitated PADs effectively decrease compulsory hospital admissions and increase mental health outcomes such as self-perceived symptoms, empowerment, and recovery.[41]

Providers have a prima facie duty to prevent harm from occurring to others, remove conditions that will cause harm to others, and help persons with disabilities.[42] This is often conceptualized within the patient-provider relationship, but it need not be. Although *general beneficence* is controversial in ethics circles, providers can promote the welfare of those they may never meet by relinquishing the responsibility of PAD facilitation to peer-support specialists.[43] In doing so, they remove the possibility of unduly influencing patient preferences, thereby reducing the risk of harm. Additionally, providers incur no additional costs, ameliorating concerns that they do not have the time or resources to facilitate PAD creation effectively.[44] Additionally, they would be implicitly endorsing a better treatment option, allowing them to meet the prima facie obligation to help persons with disabilities.

VI. Relational Autonomy and Informed Consent in PAD Creation

Shifting the burden of PAD facilitation from providers to peer-support specialists may not settle questions of undue influence. However, under their own SMI, peer-support specialists have lived experiences that strongly parallel others with SMI, which may augment patient autonomy overall. In support of this relational turn, Susan H. Williams explains: "Once the social sources of our identities are recognized, it becomes apparent that someone else who shares my culture [experience] might be able to understand me better than I understand myself." [45] Essentially, the lived experience of peer-support specialists does not necessarily impede autonomy but can effectively enhance it through facilitated support.[46] Recognizing that individuals are embedded in social relations makes it clear that conceptions of autonomy that neglect emotions, communal life, social context, interdependence, reciprocity, and the development of persons over time are exceedingly narrow.[47] Within this framework of relational autonomy, peer-support specialists can guide service users through their struggles with SMI. So long as the interaction allows service users to act intentionally, with understanding, and without external influences, professionals can respect an individual's autonomy.[48] The enhancement in service-user autonomy ultimately arises from the relationship and shared experience with the peer-support specialist.

Of course, peer-support specialists would be obligated to the affirmative duties necessary to ensure service users' understanding and informed consent. Peer-support specialists can achieve informed consent through a certification procedure and a manualized structured conversation that guides the patient to understand their preferences better.[49] To achieve informed consent, "the patient must have the capacity to be able to understand and assess the information given, communicate their choices, and understand the consequences of their decision."[50] To this end, professionals must train peer-support specialists to apply standards of competence to service users prior to PAD facilitation. Although intervening with peer-support specialists can yield substantial benefits—including fewer coercive interventions, a better-working alliance with care providers, and higher odds that individuals will receive and adhere to their preferred medications— professionals must reach informed consent during each facilitation session.[51]

VII. Guiding Distributive Justice: Capability Theory

Capability theory is an account of justice opportunity that places a fundamental moral significance on individuals' ability to reach proper functioning and well-being.[52] Whether or not an individual can make use of a particular set of resources and convert them into a state of functioning depends on personal, sociopolitical, and environmental conditions ("conversion factors").[53] In this sense, liberty is not the absence of restraint from others or institutions but the freedom achieved through capability-enhancing relationships.[54] Within the context of bioethics, capability theory shifts focus toward creating circumstances by which individuals can direct their lives as they choose.[55] Acting in accordance with the principle of beneficence, peer-support specialists could enhance the capability of patients to be self-determined and autonomous, which would promote patient well-being and empowerment.[56]

Those living with SMI, such as schizophrenia and bipolar disorder, are among the most disadvantaged in society, experiencing social and economic hardship related to their illness.[57] These individuals are often feared and rejected by others, which increases depression, lowers self-esteem, and engenders feelings of social isolation.[58] Compounding their challenges, especially for those facing structural inequalities, is insufficient access to appropriate mental health services supporting recovery.[59] Capability theory provides a sound justification for the resource distribution necessary to create and sustain a thriving network of peer-support specialists, to which those with SMI currently do not have access. Establishing this conversion factor would increase the uptake of PADs and motivate continued engagement in treatment, which is crucial for patients with SMI.[60]

Governments and private and public mental healthcare organizations should prioritize establishing peer-support facilitator networks to provide those living with SMI with this much-needed resource. Funding should be directed to train peer-support specialists so that available treatment options are clearly communicated and informed consent is achieved. NAMI Peer-to-Peer and Integral Care (Travis County) Peer Support Specialists may provide effective support models. However, policymakers should take note of Virginia's facilitation model implementation efforts and consider potential roadblocks at the state and local levels.[61] Additionally, investment should be made into a nationwide PAD repository that providers can access electronically during intake so that patient preferences are respected throughout treatment.

CONCLUSION

Those living with severe mental illness experience disproportional disadvantages that limit their ability to access mental health resources that protect their autonomy during a crisis. These disadvantages should be acknowledged and addressed with the creation and sufficient funding of peer-support specialist networks to help these individuals complete and execute psychiatric advance directives during treatment. Efforts that attempt to promote psychiatric advance directive facilitation through providers risk undue influence and poor mental health outcomes, despite the duties of non-maleficence and beneficence. While different models may be explored, peer-support specialists can leverage the advantages of their shared lived experience with patients within a framework of relational autonomy following the principle of beneficence. Capability theory offers state, local, and organizational leaders' guidance in promoting and justifying peer-support specialist networks, which protect patient autonomy, increase well-being, and decrease harm.

PERSONAL PERSPECTIVE

As someone who has voluntarily been admitted to a psychiatric health facility twice to treat manic episodes stemming from Bipolar I Disorder, I recognize the autonomy-persevering utility of psychiatric advance directives on a theoretical and experiential level. Through my research and the benefit of hindsight, I believe that a psychiatric advance directive could have facilitated my treatment regimens and perhaps mitigated some of the depersonalization and lack of control I felt. This experience informs my approach and contribution to the academic conversation surrounding the systematic barriers and ethical dilemmas preventing the widespread use of psychiatric advance directives.

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