

***The Right to Choose: The Psychiatric Patient and  
Medical Aid-in-Dying***

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ABSTRACT

With the increasing legalization of MAiD across the world, the question of whether psychiatric patients with refractory mental illness should have access to this health service is a topic of ethical debate. Even so, with present-day autonomy encouragement, and the right to die, a psychiatric diagnosis should never automatically preclude a patient from making decisions about their treatment, including the use of MAiD.

**Keywords:** End-of-Life care, Advanced Directives, Physician-Assisted Suicide, Medical Aid-in-Dying, Capacity

INTRODUCTION

Likely, no matter where we live in the world, we have similar wants: to be healthy, to be happy, to be in a community, to make our own decisions about our lives. The first and last of these wants are the primary concerns of medicine. Diseases are treated, suffering is alleviated, chronic illnesses are managed – to the extent possible. Along the way, patient autonomy is encouraged. Perhaps the greatest manifestation of this autonomy is evidenced in the increasing availability of Physician-Assisted Suicide or Medical Aid-in-Dying (MAiD). With important nuances, the criteria that patients must meet to participate in MAiD are generally similar: a patient must be over the age of 18, able to state a voluntary desire to end their own life, and two independent physicians must verify their decision-making capacity. Yet, clinical criteria for accessing this option differ. In U.S. jurisdictions where MAiD is legal, patients must have a terminal illness with a 6-month prognosis.<sup>1</sup> In Holland and Belgium, the presence of “intractable pain” is sufficient.<sup>2</sup> With the increasing legalization of MAiD across the world, the question of whether psychiatric patients suffering from refractory mental illness should have access to this means of relieving suffering is under continual debate. The ethical implications of denying autonomous decision-making to psychiatric patients at the end of life will be discussed – along with suggestions for clinical practice.

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I. Medical Aid-in-Dying and the Psychiatric Patient

There are three main arguments against allowing a patient with psychiatric suffering to pursue MAiD. The first is that patients with severe mental illness may have impaired decision-making capacity. This impaired capacity generally encompasses the following four criteria: the ability to express a choice, the ability to understand the information presented, the ability to appreciate the “medical consequences of the situation,” and the ability to engage with different choices of treatment.<sup>3</sup> These criteria are impaired to varying degrees across the spectrum of mental illnesses. For instance, about 50 percent of patients with schizophrenia hospitalized for an acute episode displayed at least one element of impaired capacity, compared with 20-25 percent of those admitted with an acute depressive episode. In contrast, depression treated on an outpatient basis may not be associated with any impairment in capacity.<sup>4</sup>

The second argument against allowing a patient with psychiatric suffering to pursue MAiD is that suicidality itself can manifest as a common symptom of psychiatric disorders (including major depressive disorder). In this context, a patient with severe mental illness who has requested MAiD, following appropriate treatment, may in fact no longer wish to die. The fear of wrongly fulfilling a MAiD request in this context alienates the notion of liberally applying MAiD to the psychiatric population. A literature review found that between 8 percent and 47 percent of patients in the Netherlands and Oregon who requested MAiD presented with depression, while 2-17 percent of those who pursued MAiD to completion had “depressive symptoms.” In the Netherlands, patients with depression were significantly less likely to be granted euthanasia/MAiD requests.<sup>5</sup> Providers are rightfully afraid of making a mistake that will cost a life. Kious and Battin phrase the dilemma simply: “When is it worse that someone die, whether from suicide or with physician assistance, who could have been helped, and when is it worse that someone whose suffering could only be alleviated by death continue to suffer?”<sup>6</sup> It is doubtful that this question will ever have a sufficient answer.

The third argument, that Calkins and Swetz fervently pose, claims that “allowing the psychiatrically ill to participate in [MAiD] will compromise the patient-clinician relationship and the relationship of medicine with the public as a whole... fundamentally alter[ing] the clinician’s role as healer and trusted advisor.”<sup>7</sup> This argument stems from western medicine’s bias of preserving life at whatever cost, the idea being that any deviation from this goal constitutes an abandonment of the patient. Calkins and Swetz’s suggestion that all patients with severe, persistent mental illness who might request MAiD do so inappropriately vastly overestimate the capacity of current psychotropic pharmacology to alleviate pain and suffering. There remain patients who have diligently run the gamut of available treatment options and remain debilitated by their disease. Allowing for participation in MAiD can instead be a testament to the strength of a patient-clinician relationship: that this patient, after presenting the topic of MAiD to their “healer and trusted advisor,” is met with a provider who willingly and carefully listens to their reasons for requesting this option, rather than rejecting the notion out of hand. If deemed appropriate, and after careful fulfillment of the remaining MAiD criteria, the relationship can then shift towards an end-of-life alliance – therapeutic in and of itself, one in which the goal is not further treatment but a peaceful end.

However, attitudes about the appropriateness of MAiD for patients with severe mental illness differ, even among psychiatrists. In a survey of 457 psychiatrists in Switzerland – one of the few countries in which MAiD can be granted “on the basis of a primary psychiatric diagnosis,” 29.3 percent of respondents indicated some degree of support for the availability of MAiD to patients with severe and persistent mental illness – an acceptance rate that parallels that of medical providers.<sup>8</sup> Among a profession dedicated to preserving life, there remains much (reasonable) caution about hastening its end.

## II. The Psychiatric Advance Directive

The ambiguity over whether patients with psychiatric illnesses should be allowed to make their own treatment decisions is not limited to the end of life. For patients with predominantly medical conditions who no longer have the capacity to make decisions about their care (for instance, patients with advanced dementia), clinicians can defer to previously stated wishes as expressed in an advance directive or per the discretion of a healthcare proxy. This deferred decision-making is sometimes referred to as *substituted judgment*.<sup>9</sup> As a correlate, patients suffering from mental illness can complete a Psychiatric Advance Directive (PAD) to indicate what treatments they would or would not want should they lose decisional capacity. These are often informed by prior, traumatic hospitalizations (for instance, a patient may request not to undergo involuntary electroconvulsive shock therapy, or receive specific antipsychotics, or may decline all psychiatric management). Yet, in contrast to advance directives guiding medical treatment, PADs are frequently (and legally) overridden if they violate “accepted clinical standards.”<sup>10</sup> At their discretion, physicians can override any part or all of a patient’s PAD if it violates what they deem to be acceptable care. Rather than a “let-the-patient-decide” law, the actual influence of PADs on clinical management is often minimal – shrinking its effect to a “let the doctor decide whether the patient gets to decide” law.<sup>11</sup>

For example, Pennsylvania’s PAD statute (Act 194) specifies three instances in which physicians can override a patient’s directive. First, a physician maintains the right to involuntarily admit a patient under civil commitment law. Second, a physician may override any part of a patient’s PAD so long as they make “every reasonable effort” to have the patient transferred to a provider willing to adhere to the patient’s request. Third, the act protects any physician who violates a patient’s PAD request from “criminal or civil liability or discipline[e] for unprofessional conduct” who is deemed to have acted in “good faith” based on accepted clinical guidelines.<sup>12</sup> In Pennsylvania’s fairly standard PAD legislation, the physician is virtually untouchable. North Carolina’s “Advance Instruction for Mental Health Treatment” documentation explicitly communicates its limitations to the patient: the opening paragraph states, “Your instructions may be overridden if you are being held in accordance with civil commitment law.”<sup>13</sup>

Of course, neither is it sustainable to adhere to all PAD requests. Consider the case of *Hargrave v. Vermont*. The Second Circuit Court of Appeals upheld the durable power of attorney (DPOA) of Nancy Hargrave (a patient with schizophrenia who was civilly committed) to refuse treatment. As Applebaum notes, “If large numbers of patients were to complete advance directives such as Nancy Hargrave’s, declining all medication, hospitals might well begin to fill with patients whom they could neither treat nor discharge.”<sup>14</sup> Notably, this case is an exception rather than the rule. Broad legislation emulating *Hargrave* will not act towards the betterment of all patients with severe mental illness. But, in the conversation on the applicability of MAiD for psychiatric patients, it is worth noting how frequently and readily these patients’ wishes are overlooked, even when they have been expressed and properly documented in a state of decisional capacity (as must be the case when completing a Psychiatric Advance Directive).

## III. The Way Forward

While those with mental illness deserve both fierce protection and robust mental health treatment, they also have a right to define what quality of life is acceptable. When determining the point at which treatment of a psychiatric illness becomes futile – and thus the option of pursuing MAiD more readily permissible – the concept of “qualitative futility” is particularly generative. Focus turns towards a patient’s first-person experience of illness and an understanding of their “subjective view about the quality of an outcome.”<sup>15</sup> This perspective shifts away from the statistical probability that a certain treatment will succeed and instead incorporates the lived reality of a patient’s illness narrative. For example, in the World Health

Organization's published report on the treatment of cancer pain, the phrase "total pain" identifies the physical and non-physical components of suffering, including "the noxious physical stimulus and also psychological, spiritual, social, and financial factors."<sup>16</sup> For severely ill patients with treatment-refractory mental illness, an understanding of "qualitative futility" and "total pain" could be the most humane way to approach who should and should not qualify for MAiD.

In one take on how patients with mental illness have the right to define what consists of an acceptable quality of life, Kious and Battin posit that if a patient's decision to pursue MAiD is voluntary and if the patient possesses decision-making capacity, their request should be granted "irrespective of whether their underlying medical diagnosis is physical or mental, terminal or nonterminal."<sup>17</sup> While this option should, of course, be withheld from patients suffering from an acute exacerbation in which the patient may not achieve decisional capacity, it is nevertheless true that psychiatric illness, even in severe cases, is often episodic, undergoing periods of remission when a patient may be symptom-free.<sup>18</sup> During these periods of lucidity, the patient's perception of quality of life should be examined with great care.

Another option offered by Kious and Battin to identify psychiatric patients who may be appropriately pursuing MAiD is to create two "metric[s] for suffering" – one for physical and one for mental illnesses. For psychiatric patients who wish to end their lives, this establishes a threshold above which suffering becomes "unbearable," opening the door for a legitimate conversation about MAiD between patient and physician (should the patient request it). Suffering below this threshold would remain grounds for involuntary admission to an inpatient facility.<sup>19</sup> The question remains: how do we gauge severe enough suffering to die and suffering that is not? In exploring this question, Zhong et al.'s understanding that a person with mental illness pursuing MAiD must be evaluated differently proves valuable. The authors suggest that rather than focusing on "point capacity" (the ability to make a specific decision), an evaluation of "global capacity" should instead be conducted - a style of evaluation that is interested in "fully contextualiz[ing]" the patient's choice to pursue MAiD. This requires asking not only about medical and psychiatric history but also family and relationship history, trauma history, education and employment history, and includes a rigorous collection of collateral information from family and friends who can confirm the patient's wishes.<sup>20</sup> An additional benefit of evaluating for "global capacity" should the choice of MAiD be followed to completion is the illumination, no matter how slight, that might be provided to relatives and friends. This prior justification for, and understanding of, the patient's decision might dull the sharpness of loss for family and friends – healing insight that may be inaccessible in the case of unassisted suicide. While Kious and Battin express concern that it is "deeply unclear" how to measure the dimensions of suffering given that "we cannot wholly trust first-person reports," these narratives nonetheless form the substrate of psychiatry and serve as the diagnostic tool of most gravitas available to providers of mental illness.<sup>21</sup> They must be trusted. Or, as the old medical adage goes, they can be *trusted and confirmed*. It is no accident that in the WHO's "Cancer Pain Relief" manual, the first step of pain assessment is to "believe the patient's complaint of pain."<sup>22</sup>

The lived experience of a patient with severe, refractory mental illness can challenge physician hesitation about the appropriateness of MAiD. In the previously cited study in which 29.3 percent of Swiss psychiatrists reported general support for the availability of MAiD in cases of refractory mental illness, the percentage curiously swelled when presented with three clinical vignettes (in each, the patient is stated to have decision-making capacity to "refuse further treatment"). In the case of a 37-year old female with a 26-year history of anorexia nervosa, ten prior hospitalizations, a weight of 52 pounds, general muscle weakness, and low bone density, who no longer wishes to undergo force-feeds, 35.4 percent of respondents indicated that they would support her choice of MAiD.<sup>23</sup> In the case of a 33-year old male with

a 16-year history of schizophrenia, who has failed numerous trials of anti-psychotic regimens and electroconvulsive shock therapy, who has “never been free from positive or negative symptoms,” and whose persisting illness has left him severely isolated, 32.1 percent indicated that they would support his choice of MAiD. And in the case of a 40-year-old male with persistent suicidal ideation for 20 years, whose symptoms have been refractory to numerous trials of anti-depressants, anti-psychotics, mood stabilizers, combination therapy, psychotherapy, and electroconvulsive shock therapy, who plans to commit suicide “in the near future,” 31.4 percent of respondents indicated that they would support his choice of MAiD.

With generous and nuanced attention to a patient’s “total pain,” following careful evaluation of their “global capacity,” and after a thorough review of all treatment trials and any available therapeutic options yet un-tried (assessing “psychiatric futility”), those who are suffering from severe, refractory mental illness should be granted similar access to MAiD as patients suffering from cancer, ALS, and other organic causes of disease. We cannot adequately police the “badness of suffering.”<sup>24</sup>

## CONCLUSION

In summary, a psychiatric diagnosis should never automatically preclude a patient from making decisions about their treatment, including deciding to end one’s own life with the help of a licensed provider. Medical Aid-in-Dying is associated with a safe, certain, and painless death. In the circumstances where it would be applicable, it serves as a less fraught option than unassisted suicide. We owe anyone who is ceaselessly suffering that much. Or, at the very least, we owe this equally fraught topic an honest conversation.

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<sup>7</sup> Calkins, Bethany C., and Keith M. Swetz. “Physician Aid-in-Dying and Suicide Prevention in Psychiatry,” 68–70.

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<sup>11</sup> Swanson, Jeffrey W et al. "Superseding Psychiatric Advance Directives," 385-94.

<sup>12</sup> Ibid

<sup>13</sup> "Advance Directive for Mental Health Treatment." *NC Secretary of State*. Web. 13 July 2021.

<[https://www.sosnc.gov/forms/by\\_title/\\_advance\\_healthcare\\_directives](https://www.sosnc.gov/forms/by_title/_advance_healthcare_directives)>.

<sup>14</sup> Appelbaum, Paul S. "Law & Psychiatry: Psychiatric Advance Directives and the Treatment of Committed Patients." *Psychiatric Services (Washington, D.C.)* vol. 55, no. 7, 2004, pp. 751–763. doi:10.1176/appi.ps.55.7.751

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<sup>16</sup> World Health Organization. (1986). Cancer Pain Relief. World Health Organization. <https://apps.who.int/iris/handle/10665/43944>

<sup>17</sup> Kious, Brent M., and Margaret (Peggy) Battin. "Physician Aid-in-Dying and Suicide Prevention in Psychiatry: A Moral Crisis?" *The American Journal of Bioethics*, vol. 19, no. 10, 2019, pp. 29–39, doi:10.1080/15265161.2019.1653397.

<sup>18</sup> Kious, Brent M., and Margaret (Peggy) Battin. "Physician Aid-in-Dying," 29–39.

<sup>19</sup> Ibid

<sup>20</sup> Appelbaum, Paul S. "Law & Psychiatry," 751–763.

<sup>21</sup> Kious, Brent M., and Margaret (Peggy) Battin. "Physician Aid-in-Dying," 29–39.

<sup>22</sup> World Health Organization, Cancer Pain Relief.

<sup>23</sup> Hodel, Martina A et al. "Attitudes Toward Assisted Suicide Requests," 621-627.

<sup>24</sup> Kious, Brent M., and Margaret (Peggy) Battin. "Physician Aid-in-Dying," 29–39.