Suffering is not enough: Assisted dying for people with mental illness

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Abstract
Persons with mental disorders who are resistant to evidence-based treatment can be referred to as patients with severe and persistent mental illness (SPMI). Some patients with SPMI develop a strong wish for assisted dying. Switzerland has the longest history of non-medicalized assisted dying, which is considered a civil right even in non-pathological situations. Public debate in Switzerland about the issue of suffering in the context of assisted dying is current and ongoing. The Swiss Academy of Medical Sciences recently revised its end-of-life policy and specified intolerable suffering due to severe illness or functional limitations (and acknowledged as such by a physician) as a core criterion for assisted dying. We argue that suffering is a necessary but insufficient condition for assisted dying, and that the criteria should also include decision-making capacity and refractoriness of suffering. We further contend that suffering is a subjective experience that can only be quantified by the patient and cannot be objectively compared across individuals. Some patients with SPMI and refractory suffering who maintain decision-making capacity will meet the criteria for assisted dying. We advocate for palliative psychiatric care that relinquishes any disease-modifying therapy, accepts limited survival chances, and focuses on measures that enhance the patient’s quality of life, understood in a very broad sense beyond only health-related quality of life. This approach should also relieve suffering as much as possible while remaining open to the possibility of assisted dying following conscientious assessment of the criteria.

KEYWORDS
assisted suicide, decision-making capacity, ethics, futility, medical assistance in dying, mental illness

1 INTRODUCTION

Persons with mental disorders who are resistant to evidence-based treatment can be referred to as patients with severe and persistent mental illness (SPMI).1 For example, some patients with depression are resistant to all kinds of evidence-based psychiatric treatment, including medication, psychosocial interventions, psychotherapeutic approaches particularly designed for chronic depression such as the cognitive behavioral analysis...
system of psychotherapy (CBASP), and pharmacological last-resort treatments such as electroconvulsive therapy and ketamine infusion. Frequently, the chances of partial remission decrease with each additional treatment attempt. This is the case not only for severe and chronic depression but also for severe and persistent bipolar disorder, schizophrenia, and anorexia nervosa. Some persons with SPMI may consider their quality of life to be low, have substantial comorbidity, and be highly dependent on healthcare services.

As most treatments can be considered medically futile for some patients with SPMI, other models such as the recovery approach or palliative care have been suggested as an alternative to curative treatments. Of course, assisted dying (AD) should never be suggested or used as a competitor to adequate care, but could be considered in cases where adequate care has failed to provide sufficient relief of the patient’s suffering.

Furthermore, as some patients with SPMI develop a strong wish for hastened death in the course of their illness, some authors have argued for access to AD as an exceptional option for those patients who request it and meet certain eligibility criteria (see below). It is therefore important to investigate the ethical question of whether to grant access to AD to patients with SPMI. This issue received some attention in the philosophical literature several years ago and again recently. However, only a few psychiatric ethics scholars have broached the issue.

A number of jurisdictions (including the Netherlands, Belgium, Luxembourg, and Switzerland) already permit forms of AD for persons with SPMI, or exempt participating physicians from criminal liability. In Switzerland, assisted suicide (but not euthanasia) is legally allowed unless for selfish motives, and as such is also available to patients with SPMI as long as they possess the respective decision-making capacity (DMC). In these jurisdictions, requests for AD have increased in recent years, both in general and from persons with SPMI. In the Netherlands in 2018, 11% (N = 67) of all cases (n = 6126) of AD related to mental illness. In Belgium, cases of euthanasia among psychiatric patients had risen steadily to 3% by 2013. In Switzerland, the rate since 2006 has been even higher: 8% of all AD cases among Swiss residents and 17% of cases among foreign nationals had documented mental disorders.

2 INTOLERABLE SUFFERING AS A NECESSARY BUT INSUFFICIENT CRITERION FOR ASSISTED DYING

Amid ongoing public debate in Switzerland about AD, the Swiss Academy of Medical Sciences recently revised its end-of-life policy for healthcare professionals. As a result, intolerable suffering due to...
severe illness or functional limitations as acknowledged by a physician became a core criterion for AD. However, physicians and other experts differ regarding the exact meaning and assessment of “intolerable suffering,” indeed, there are no objective epistemological criteria either for suffering in general or for intolerable suffering in particular. As suffering is inherently subjective, it can only be fully appraised by those who are suffering, and it would seem odd for a healthcare professional to question or deny a suffering that the patient feels or to judge that a suffering patient is not suffering “enough” to warrant the label of “intolerable suffering.” In general, intolerable suffering can be defined as “[...] a subjective experience of suffering that is so serious and uncontrollable that it overwhelms one’s bearing capacity [...]” In short, the notion of intolerable suffering is an irreducibly subjective reality that cannot be ultimately confirmed or denied by others, although it can be more or less understood.

In our view, it is therefore problematic when the Swiss Academy of Medical Sciences, as well as legislators in Belgium and the Netherlands, use the notion of intolerable suffering as a key condition for access to AD by empowering physicians to evaluate it from the outside. Rather, the responsible healthcare professional should explore the suffering of the patient with humility as carefully and diligently as possible in order to better understand it. Instead of wanting to prove or disprove the intolerability of suffering, trying to understand why the patient considers their suffering intolerable and whether this situation is persistent is much more in line with the professional duty of care and the respect for autonomy.

Even if the existence of intolerable suffering is accepted as a condition for access to AD, it is certainly not sufficient from an ethical point of view. As a sole criterion, it may even lead to ethically problematic decisions. While many AD requests are clearly motivated by unbearable suffering and a wish to hasten death, this might not always be the case. If, for example, someone is pressurized to request AD against his or her will or someone’s suffering is momentarily intolerable but unsteady and likely to ease soon, it might run contrary to the patient’s autonomy and the patient’s best interest to receive AD. Therefore, we contend that intolerable suffering can be a motivation for the wish to hasten death but is not a sufficient condition for getting access to AD. That being so, two other criteria are needed: the patient must have DMC, and his or her suffering must be treatment-refractory in nature.

3 | DECISION-MAKING CAPACITY AS A CRITERION FOR ASSISTED DYING

DMC is seen as the gatekeeping element for a patient’s right to self-determination, especially in the context of healthcare decisions, and is an indispensable condition for eligibility for AD. Doubts about a patient’s DMC often arise in relation to those with mental disorders such as depression, schizophrenia, or bipolar disorder. For example, large-scale studies have shown that 20%–31% of persons with depression lack DMC in relation to major treatment decisions, and 58% of psychiatrists expressed the view that a diagnosis of major depressive disorder would imply a priori that the patient lacks DMC. As some patients with mental disorders suffer intensely or even intolerably, one may think that this implies that they are incapable of making their own healthcare and end-of-life decisions.

Based on the above findings, however, this view is obviously wrong, as DMC cannot be directly or conclusively inferred from suffering itself or from a particular diagnostic category, including depression, and, in fact, many mental states including intolerable suffering are compatible with preserved DMC. One systematic review confirmed that depression can influence DMC but does not always render the patient incompetent, and a recent meta-review established that up to 75% of psychiatric patients may have DMC to make their own healthcare decisions. As a function of the fluctuating symptoms of various mental disorders (e.g., cognitive or emotional fluctuation), DMC may also fluctuate over time; that is, one and the same person can have intact DMC at some times, while this may not be the case at other times.

Even if a decision about AD can reasonably be said to demand a higher threshold, it seems clear that some patients with SPMI, at certain times during their disease course, exhibit the necessary DMC.
to decide about AD. Nevertheless, a diagnosis of SPMI may of course introduce substantial doubt about the patient’s DMC, which must then be assessed for a number of reasons:

We should prevent patients who are mentally in-competent in harming themselves; in this case, the harm would consist in helping them end their lives when they are not fit to make such a decision. The principle of respect for autonomy tells us that we should not prevent patients who can make autonomous decisions from accessing assisted suicide if they wish to do so. Similarly, the principle of non-maleficence indicates that we should not inflict harm upon patients who are mentally competent by insisting that they remain alive and suffering.36

At present, it is relatively easy for physicians who are personally opposed to AD to decline it by denying DMC and declaring the patient legally incompetent to make such a decision. However, seeking to prevent a patient with preserved DMC from accessing AD is unduly paternalistic and runs contrary to the patient’s right to autonomy as established in biomedical ethics and in society at large. While any healthcare professional is entitled to invoke his or her right to conscientious objection regarding an involvement in AD, it is unprofessional and unethical in a pluralistic society to impose those same values on patients or on other healthcare professionals.37 Whatever their personal moral attitude to AD, healthcare providers must be able to deal with a request for AD in a professional manner. In our view, this includes the ethical obligation to refer the patient to another colleague willing to assume this responsibility.

4 | REFRACTORINESS OF SUFFERING AS A SECOND CRITERION FOR ASSISTED DYING

A second proposed criterion for AD is refractoriness of suffering. This concept, which is based on the principle of beneficence and implies that any alternative, potentially beneficial treatment should have been ruled out, is relatively easy to apply in the context of pain management or control of other somatic symptoms.38 It becomes, however, significantly more difficult in cases of mental disorders because communication of suffering is less straightforward and the range and effects of potential treatments are wider than is typically the case for somatic diseases.39 As an example, while it is relatively straightforward to assess whether a bacterial infection is sensitive or refractory to an antibiotic, the same cannot be said for a mental disorder and psychotherapy.

One current source of debate is whether and how one can identify patients whose disease course is inexorably terminal. This uncertainty is a major issue in the debate around AD for patients with mental disorders;40 for example, survey data from the Netherlands indicate that psychiatrists disagree about irremediability in almost 20% of cases where patients request AD.41 Accordingly, some scholars insist that the concept of medical futility is fundamentally inapplicable to mental disorders because of this high prognostic uncertainty.42 Additionally, judged futility may impact negatively on caregivers’ attitudes and behaviors.43 However, other clinical studies have concluded that some patients with SPMI will demonstrably never recover, and that any further therapeutic input is therefore medically futile.44 In their pioneering article, Lopez, Yager, and Feinstein specified four criteria for medical futility in the context of mental disorders: (1) poor prognosis; (2) unresponsiveness to competent treatment; (3) continued physiological and psychological decline; and (4) apparently inexorable terminal course.45 On this view, those criteria may be met by some psychiatric patients who request AD.

However, particularly the fourth criterion of an “apparently inexorable terminal course” may suggest that certain persons with SPMI are likely to die soon from their mental illness. With the exception of patients with anorexia nervosa, taken as the illustrating example by Lopez and colleagues,46 most patients do not die from their SPMI directly but rather indirectly, yet prematurely, through suicide (e.g., in affective disorders), risk behavior, or somatic complications of their mental illness: “Despite common misassumptions that most individuals with SPMI die prematurely from violence and suicide, the majority of excess mortality is due to chronic diseases such as cancer, heart disease, chronic obstructive pulmonary disease, and dementia.”47

Thus, at first sight, the fourth criterion for medical futility by Lopez and colleagues may not be of much help for determining

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36Shaw, D., Trachsel, M., & Elger, B. (2018). Assessment of decision-making capacity in patients requesting assisted suicide. British Journal of Psychiatry, 213(1), 393–395. https://doi.org/10.1192/bjp.2018.81, p. 394.
37Ibid.
38Wolff, C. A., & Trachsel, M. (2018). Pain and symptom control in palliative care: A meta-analysis. International Journal of Palliative Nursing, 24(10), 499–505.
39Shalev, D., Brewster, K., Arluck, M. R., & Levinson, J. A. (2017). A staggered edge: End-of-life care in patients with severe mental illness. General Hospital Psychiatry, 44, 1–3. https://doi.org/10.1016/j.genhosppsych.2016.10.004, p. 372.
40Lopez, A., Yager, J., & Feinstein, R. E. (2010). Medical futility and psychiatry: Palliative care and hospice care as a last resort in the treatment of refractory anorexia nervosa. International Journal of Eating Disorder, 43(4), 372–377. https://doi.org/10.1002/eat.20701
41Ibid.
42Ibid.
43Shalev, D., Brewster, K., Arluck, M. R., & Levinson, J. A. (2017). A staggered edge: End-of-life care in patients with severe mental illness. General Hospital Psychiatry, 44, 1–3. https://doi.org/10.1016/j.genhosppsych.2016.10.004, p. 372.
44Ibid.
45Ibid.
46Ibid.
47Ibid.
refractoriness of suffering. At second sight, the notion of terminal illness in psychiatry does not necessarily need to be understood as a high risk to die soon from the SPMI. Levitt and Buchman have suggested that terminal illness in psychiatry "can be understood as a condition in which ongoing interventions do not produce meaningful change in symptoms such that a patient deems their quality of life as unacceptable."48 In this view, the notion of terminal illness does not need to solely relate to an end-of-life context. “There may be tacit acceptance among psychiatrists that there is a terminal quality to some SPMI.”49 In a survey of psychiatrists in Switzerland, 94.5% of respondents indicated that SPMI could be considered a terminal illness.50 To determine refractoriness of suffering, it may thus nonetheless make sense to apply the criteria for medical futility suggested by Lopez and colleagues with specifying the fourth criterion of an "apparently inexorable terminal course" by the definition of a terminal illness in psychiatry from Levitt and Buchman: "a condition in which ongoing interventions do not produce meaningful change in symptoms such that a patient deems their quality of life as unacceptable."51

5 | THE CAUSE OF SUFFERING IS NOT A RELEVANT CRITERION FOR ACCESS TO ASSISTED DYING

To argue that access to AD should be allowed only when physical pain or other somatic symptoms lead to unbearable suffering would in fact discriminate unfairly against patients with mental disorders. According to Cassell, "[s]uffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity."49 In other words, suffering is not confined to the physical dimension but also encompasses psychological, existential, and spiritual dimensions.53 On this view, what transforms pain or dyspnea into suffering is not sensory perception but the emotional and existential impacts of that perception. That emotional and existential distress may also be caused by a mental disorder, perhaps to an even greater extent.

In a recently published article (boldly entitled "Nothing hurts less than being dead"), Lengvenyte and colleagues identified several dimensions of psychological pain causing suffering in individuals who requested AD.54 Building on the principle that the cause of suffering is irrelevant for access to AD, Schuklenk and van de Vathorst argued that "[i]n the context of decision to hasten death and the refractoriness of suffering to the available treatment options. As this latter concept is difficult to apply in cases of mental disorder, especially given the fluctuating nature of many disorders, it seems important to develop clear procedural guidelines for assessing the refractoriness of the most relevant mental disorders. In this way, the criteria for AD will be met by some patients with SPMI: intolerable, refractory suffering, and preserved DMC.

6 | CONCLUSION: AN ETHICAL ARGUMENT FOR ACCESS TO ASSISTED DYING FOR PERSONS WITH SEVERE AND PERSISTENT MENTAL ILLNESS

While an increasing number of countries permit AD, the issue of whether patients with SPMI should be granted such access remains contentious. In arguing for access to AD for these patients, we do not concur with the mainstream ethical justification; in other words, even though intolerable suffering is often inherent in the wish for hastened death, it is not sufficient as a condition to access AD, and, owing to its subjective nature, it cannot be fully appraised and objectively proven or disproven by others. It remains important to explore this suffering with humility as carefully and diligently as possible and to try to understand it from the perspective of the patient.

In addition to the criterion of intolerable suffering, we argue that access to AD should be based on a rigorous assessment of DMC specifically in the context of the decision to hasten death and the refractoriness of suffering to the available treatment options. As this latter concept is difficult to apply in cases of mental disorder, especially given the fluctuating nature of many disorders, it seems important to develop clear procedural guidelines for assessing the refractoriness of the most relevant mental disorders. In this way, the criteria for AD will be met by some patients with SPMI: intolerable, refractory suffering, and preserved DMC.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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55Schuklenk, U., & van de Vathorst, S. (2015). Treatment-resistant major depressive disorder and assisted dying. Journal of Medical Ethics, 41(8), 577–583. https://doi.org/10.1136/medethics-2014-102458, p. 577.
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