

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

Manuel Trachsel^{1,2,3} and Ralf J. Jox^{4,5}

¹Institute of Biomedical Ethics and History of Medicine, University of Zurich, Zurich, Switzerland

²Clinical Ethics Unit, University Hospital Basel, Switzerland, Basel,

³Clinical Ethics Unit, University Psychiatric Clinics, Basel, Switzerland

⁴Institute of Humanities in Medicine, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland

⁵Palliative and Supportive Care Service, Chair in Geriatric Palliative Care, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland

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 different 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

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

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),² and pharmacological last-resort treatments such as electroconvulsive therapy³ and ketamine infusion.⁴ Frequently, the chances of partial remission decrease with each additional treatment attempt.⁵ This is the case not only for severe and chronic depression but also for severe and persistent bipolar disorder,⁶ schizophrenia,⁷ or anorexia nervosa.⁸ Some persons with SPMI may consider their quality of life to be low, have substantial comorbidity, and are highly dependent on healthcare services.⁹

¹ Zumstein, N., & Riese, F. (2020). Defining Severe and Persistent Mental Illness-A Pragmatic Utility Concept Analysis. *Front Psychiatry*. 11, 648. <https://doi.org/10.3389/fpsy.2020.00648>

² Negt, P., Brakemeier, E. L., Michalak, J., Winter, L., Bleich, S., & Kahl, K. G. (2016). The treatment of chronic depression with cognitive behavioral analysis system of psychotherapy: a systematic review and meta-analysis of randomized-controlled clinical trials. *Brain and Behavior*. 6(8). e00486. <https://doi.org/10.1002/brb3.486>

³ Lima, N. N., Nascimento, V. B., Peixoto, J. A., Moreira, M. M., Neto, M. L., Almeida, J. C., ... Reis, A. O. (2013). Electroconvulsive therapy use in adolescents: A systematic review. *Ann Gen Psychiatry*. 12(1), 17. doi:10.1186/1744-859X-12-17

⁴ Andrade, C. (2017). Ketamine for depression, 4: In what dose, at what rate, by what route, for how long, and at what frequency? *J Clin Psychiatry*. 78(7), e852-e857. doi:10.4088/JCP.17f11738

⁵ Rush, A. J., Trivedi, M. H., Wisniewski, S. R., Nierenberg, A. A., Stewart, J. W., Warden, D., ... Fava, M. (2006). Acute and longer-term outcomes in depressed outpatients requiring one or several treatment steps: A STAR*D report. *Am J Psychiatry*. 163(11), 1905–1917. doi:10.1176/ajp.2006.163.11.1905

⁶ Gitlin M. (2006). Treatment-resistant bipolar disorder. *Mol Psychiatry*. 11(3), 227–240. <https://doi.org/10.1038/sj.mp.4001793>

⁷ Kennedy, J. L., Altar, C. A., Taylor, D. L., Degtiar, I., & Hornberger, J. C. (2014). The social and economic burden of treatment-resistant schizophrenia: A systematic literature review. *Int Clin Psychopharmacol*. 29(2), 63–76. doi:10.1097/YIC.0b013e32836508e6

⁸ Yager J. (2020). Managing patients with severe and enduring anorexia nervosa: when is enough, enough? *The J Nerv Ment Dis*. 208(4), 277–282. <https://doi.org/10.1097/NMD.0000000000001124>

⁹ Berk, M., Singh, A., & Kapczinski, F. (2008). When illness does not get better: Do we need a palliative psychiatry? *Acta Neuropsychiatr*. 20, 165–166. doi:10.1111/j.1601-5215.2008.00309.x

As most treatments can be considered medically futile for some patients with SPMI,¹⁰ other models such as the recovery approach¹¹ or palliative care have been suggested as an alternative to curative treatments.¹² Of course, assisted dying should never be suggested or used as an alternative to adequate care, but could be considered if 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 assisted dying (AD) as an exceptional option¹³ for those patients who request it and meet certain eligibility criteria (see below).¹⁴ It is therefore important to investigate the ethical question of whether to grant access to AD for patients with SPMI. This issue received some attention in the philosophical literature several years ago^{15,16,17,18} and again recently.¹⁹ However, only a few psychiatric ethics scholars have broached the issue.^{20,21,22}

A number of jurisdictions (including the Netherlands, Belgium, Luxembourg, and Switzerland) already permit forms of AD for persons with SPMI or exempt participating

¹⁰ Levitt, S., & Buchman, D. Z. (2020). Applying futility in psychiatry: a concept whose time has come. *J Med Ethics*. medethics-2020-106654. Advance online publication. <https://doi.org/10.1136/medethics-2020-106654>

¹¹ Jaeger, M., & Hoff, P. (2012). Recovery: Conceptual and ethical aspects. *Curr Opin Psychiatry*. 25(6), 497–502. doi:10.1097/YCO.0b013e328359052f

¹² Trachsel, M., Irwin, S. A., Biller-Andorno, N., Hoff, P., & Riese, F. (2016). Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks. *BMC Psychiatry*. 16, 260. doi:10.1186/s12888-016-0970-y

¹³ AD encompasses both euthanasia and assisted suicide. In euthanasia, the physician administers the drug; in assisted suicide, the physician only prescribes the drug, and the patient takes it autonomously.

¹⁴ Vandenberghe, J. (2018). Physician-assisted suicide and psychiatric illness. *N Engl J Med*. 378(10), 885–887. doi:10.1056/NEJMp1714496

¹⁵ Appel, J. M. (2007). A suicide right for the mentally ill? A Swiss Case Opens a New Debate. *The Hastings Center Report*, 37(3), 21–23. doi:10.1353/hcr.2007.0035

¹⁶ Hewitt, J. (2013). Why are people with mental illness excluded from the rational suicide debate? *Int J Law Psychiat*. 36(5-6), 358–365. doi:10.1016/j.ijlp.2013.06.006

¹⁷ Parker, M. (2013). Defending the indefensible? Psychiatry, assisted suicide and human freedom. *Int J Law Psychiat*. 36(5-6), 485–497. doi:10.1016/j.ijlp.2013.06.007

¹⁸ Cholbi, M. J. (2013). The terminal, the futile, and the psychiatrically disordered. *Int J Law Psychiat*. 36(5-6), 498–505. doi:10.1016/j.ijlp.2013.06.011

¹⁹ Maung, H. (2020). Psychiatric euthanasia and the ontology of mental disorder. *J Appl Philos*. doi:10.1111/japp.12462

²⁰ Vandenberghe, op. cit. note 15.

²¹ Miller, F. G., & Appelbaum, P. S. (2018). Physician-assisted death for psychiatric patients—Misguided public policy. *N Engl J Med*. 378(10):883–885. doi:10.1056/NEJMp1709024

²² Appelbaum P. S. (2018). Physician-assisted death in psychiatry. *World psychiatry: official journal of the World Psychiatric Association (WPA)*, 17(2), 145–146. doi.org/10.1002/wps.20548

physicians from criminal liability.^{23,24,25} 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.²⁶ In these jurisdictions, requests for AD have increased in recent years, both in general and from persons with SPMI.²⁷ In the Netherlands in 2018, 1.1% ($N = 67$) of all cases ($n = 6'126$) of AD related to mental illness.^{28,29} In Belgium, cases of euthanasia among psychiatric patients had risen steadily by 2013 to 3%.³⁰ In Switzerland, the rate since 2006 is even higher; 8% of all AD cases among Swiss residents and 17% of cases among foreign nationals had documented mental disorders.³¹

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 health care professionals. As a result, *intolerable suffering* due to severe illness or functional limitations as acknowledged by a physician became a core criterion for AD.³² However, physicians and other experts differ

²³ Dyer, O., White, C., & García Rada, A. (2015). Assisted dying: Law and practice around the world. *BMJ*. 351, h4481. doi:10.1136/bmj.h4481

²⁴ Emanuel, E. J., Onwuteaka-Philipsen, B. D., Urwin, J. W., & Cohen J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA*. 316(1), 79–90. doi:10.1001/jama.2016.8499

²⁵ Kim, S. Y., De Vries, R. G., & Peteet, J. R. (2016). Euthanasia and assisted suicide of patients with psychiatric disorders in the Netherlands 2011 to 2014. *JAMA Psychiatry*. 73(4), 362–368. doi: 10.1001/jamapsychiatry.2015.2887

²⁶ Emanuel et al., op. cit. note 24.

²⁷ Borasio, G. D., Jox, R. J., & Gamondi, C. (2019). Regulation of assisted suicide limits the number of assisted deaths. *Lancet*. 393(10175), 982–983. doi:10.1016/S0140-6736(18)32554-6

²⁸ Kim et al., op. cit. note 25.

²⁹ *Dutch Regional Euthanasia Review Committee annual report 2018*. Retrieved from https://english.euthanasiecommissie.nl/binaries/euthanasiecommissie-en/documents/publications/annual-reports/2002/annual-reports/annual-reports/RTE_jv2018_English.pdf

³⁰ Dierickx, S., Deliens, L., Cohen, J., & Chambaere, K. (2017). Euthanasia for people with psychiatric disorders or dementia in Belgium: Analysis of officially reported cases. *BMC Psychiatry*. 17(1), 203. doi:10.1186/s12888-017-1369-0

³¹ Bartsch, C., Landolt, K., Ristic, A., Reisch, T., & Ajdacic-Gross, V. (2019). Assisted suicide in Switzerland: An analysis of death records from Swiss institutes of forensic medicine. *Dtsch Arztebl Int*. 116(33-34), 545–552. doi:10.3238/arztebl.2019.0545

³² Swiss Academy of Medical Sciences. (2018). *Medical-ethical guidelines and recommendations on the management of dying and death*. Bern, Switzerland.

regarding the exact meaning and assessment of “intolerable suffering”;³³ 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,^{34,35,36} and it would seem odd for a health care 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 [...]”.³⁷ 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 key condition for access to AD by empowering physicians to evaluate it from the outside.³⁸

Rather, the responsible health care professional should explore the suffering of the patient with humility as careful and diligent 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 his suffering intolerable and whether this situation is persistent are much more in line with the professional duty of care and the respect for autonomy.

³³ Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Elwyn, G., Vissers, K. C., & van Weel, C. (2013). Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives and treating physicians in the Netherlands. *Palliat Med.* 27(1), 27–37. doi:10.1177/0269216312463259

³⁴ Cassell, E. J. (1982). The nature of suffering and the goals of medicine. *N Engl J Med.* 306(11), 639–645. doi:10.1056/NEJM198203183061104

³⁵ Shaffer, C. S., Cook, A. N., & Connolly, D. A. (2016). A conceptual framework for thinking about physician-assisted death for persons with a mental disorder. *Psychology, Public Policy, and Law.* 22(2), 141–157. doi:10.1037/law0000082

³⁶ Wijsbek, H. (2012). The subjectivity of suffering and the normativity of unbearableness. In S. Youngner & G. Kimsma (Eds.), *Physician-assisted death in perspective: assessing the Dutch experience* (pp. 319–332). Cambridge: Cambridge University Press. doi:10.1017/CBO9780511843976.029

³⁷ Ruijs, K. D., Onwuteaka-Philipsen, B. D., van der Wal, G., & Kerkhof, A. J. (2009). Unbearability of suffering at the end of life: The development of a new measuring device, the SOS-V. *BMC Palliat Care.* 8, 16. doi:10.1186/1472-684X-8-16. p.2

³⁸ Swiss Academy of Medical Sciences, op. cit. note 32.

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 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 of the wish to hasten death but is not a sufficient condition for controlling access to AD. That being so, two other criteria are needed: the patient must have decision-making capacity, and his or her suffering must be treatment-refractory in nature.

Decision-making capacity as a criterion for assisted dying

Decision-making capacity (DMC) is seen as the gatekeeping element for a patient's right to self-determination, especially in the context of healthcare decisions³⁹ 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,^{40,41} and 58% of psychiatrists expressed the view that a diagnosis of major depressive disorder would imply *a priori* that the patient lacks DMC.⁴² As some patients with mental disorders suffer intensely or even intolerably, one may think that this implies being incapable of making their own healthcare and end-of-life decisions.

³⁹ Hermann, H., Feuz, M., Trachsel, M., & Biller-Andorno, N. (2020). Decision-making capacity: From testing to evaluation. *Med Health Care Philos.* 23(2), 253–259. doi:10.1007/s11019-019-09930-6

⁴⁰ Grisso, T., & Appelbaum, P. S. (1995). The MacArthur treatment competence study. III. *Law Hum Behav.* 19(2), 149–174. doi:10.1007/BF01499323

⁴¹ Hindmarch, T., Hotopf, M., & Owen, G. S. (2013). Depression and decision-making capacity for treatment or research: A systematic review. *BMC Med Ethics.* 14, 54. doi:10.1186/1472-6939-14-54

⁴² Ganzini, L., Leong, G. B., Fenn, D. S., Silva, J. A., & Weinstock, R. (2000). Evaluation of competence to consent to assisted suicide: Views of forensic psychiatrists. *Am J Psychiatry* 157(4), 595–600. doi:10.1176/appi.ajp.157.4.595

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.⁴³ One systematic review confirmed that depression can influence DMC but does not always render the patient incompetent,⁴⁴ and a recent meta-review established that up to 75% of psychiatric patients may have DMC to make their own healthcare decisions.⁴⁵ As a function of the fluctuating symptoms of various mental disorders (e.g., cognitive or emotional fluctuation), DMC may also fluctuate over time, i.e., one and the same person can have intact DMC at times, while it may not be the case at some other times.⁴⁶ 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 incompetent from 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.⁴⁷

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.

⁴³ Okai, D., Owen, G., McGuire, H., Singh, S., Churchill, R., & Hotopf, M. (2007). Mental capacity in psychiatric patients: Systematic review. *Br J Psychiatry*. 191, 291–297. doi:10.1192/bjp.bp.106.035162

⁴⁴ Hindmarch et al., op. cit. note 41.

⁴⁵ Calcedo-Barba, A., Fructuoso, A., Martinez-Raga, J., Paz, S., Sánchez de Carmona, M., & Vicens, E. (2020). A meta-review of literature reviews assessing the capacity of patients with severe mental disorders to make decisions about their healthcare. *BMC Psychiatry*. 20(1), 339. doi:10.1186/s12888-020-02756-0

⁴⁶ Trachsel, M., Hermann, H., & Biller-Andorno, N. (2015). Cognitive fluctuations as a challenge for the assessment of decision-making capacity in patients with dementia. *Am J Alzheimers Dis Other Demen*. 30(4), 360–363. <https://doi.org/10.1177/1533317514539377>

⁴⁷ Shaw, D., Trachsel, M., & Elger, B. (2018). Assessment of decision-making capacity in patients requesting assisted suicide. *Br J Psychiatry*. 213(1), 393–395. doi:10.1192/bjp.2018.81. p. 394

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 health care 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 health care professionals.⁴⁸ Whatever their personal moral attitude to AD, health care 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.

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.⁴⁹ It but 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.⁵⁰ 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

⁴⁸ Ibid.

⁴⁹ Riley, J., Branford, R., Droney, J., Gretton, S., Sato, H., Kennett, A., et al. (2015). Morphine or oxycodone for cancer-related pain? A randomized, open-label, controlled trial. *J Pain Symptom Manage.* 49(2), 161–172. <https://doi.org/10.1016/j.jpainsymman.2014.05.021>

⁵⁰ Moriana, J. A., Gálvez-Lara, M., & Corpas, J. (2017). Psychological treatments for mental disorders in adults: A review of the evidence of leading international organizations. *Clin Psychol Rev.* 54, 29–43. <https://doi.org/10.1016/j.cpr.2017.03.008>

patients with mental disorders;⁵¹ for example, survey data from the Netherlands indicate that psychiatrists disagree about irremediability in almost 20% of cases where patients request AD.⁵² Accordingly, some scholars insist that the concept of medical futility is fundamentally inapplicable to mental disorders because of this high prognostic uncertainty.⁵³ Additionally, judged futility may impact negatively on caregivers' attitudes and behaviors.⁵⁴ 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.⁵⁵ 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.⁵⁶ 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 anorexia nervosa taken as the illustrating example by Lopez and colleagues,⁵⁷ most other 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

⁵¹ van Veen, S. M. P., Ruissen, A. M., & Widdershoven, G. A. M. (2020). Irremediable psychiatric suffering in the context of physician-assisted death: A scoping review of arguments. *Can J Psychiatry*. 706743720923072 [published online ahead of print]. doi:10.1177/0706743720923072

⁵² Kim et al., op. cit. note 25.

⁵³ Pies, R. W. (2015). Anorexia nervosa, "futility," and category errors. *Am J Bioeth*. 15(7), 44–46. doi:10.1080/15265161.2015.1039734

⁵⁴ Ibid.

⁵⁵ Dembo, J., Schuklenk, U., & Reggler, J. (2018). "For their own good": A response to popular arguments against permitting medical assistance in dying (MAID) where mental illness is the sole underlying condition. *Can J Psychiatry*. 63(7), 451–456. doi:10.1177/0706743718766055

⁵⁶ Lopez, 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. *Int J Eat Disord*. 43(4), 372–377. doi:10.1002/eat.20701

⁵⁷ Ibid.

diseases such as cancer, heart disease, chronic obstructive pulmonary disease, and dementia.”⁵⁸

Thus, at first sight, the fourth criterion for medical futility by Lopez and colleagues may not be of much help for determining refractoriness of suffering. At second sight, the notion of terminal illness in psychiatry doesn’t 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.”⁵⁹ In this view, the notion of terminal illness doesn’t 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.”⁶⁰ In a survey of psychiatrists in Switzerland, 94.5% of respondents indicated that SPMI could be considered a terminal illness.⁶¹ To determine refractoriness of suffering, it may be 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.”⁶²

The cause of suffering is not a relevant criterion for access to AD

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

⁵⁸ Shalev, D., Brewster, K., Arbuckle, M. R., & Levenson, J. A. (2017). A staggered edge: End-of-life care in patients with severe mental illness. *Gen Hosp Psychiatry, 44*, 1–3. <https://doi.org/10.1016/j.genhosppsy.2016.10.004>. p. 372

⁵⁹ Levitt, S., & Buchman, D. Z. (2020). Applying futility in psychiatry: a concept whose time has come. *J Med Ethics, medethics-2020-106654*. Advance online publication. <https://doi.org/10.1136/medethics-2020-106654>. p. 3.

⁶⁰ Ibid. p. 3.

⁶¹ Trachsel, M., Hodel, M. A., Irwin, S. A., Hoff, P., Biller-Andorno, N., & Riese, F. (2019). Acceptability of palliative care approaches for patients with severe and persistent mental illness: a survey of psychiatrists in Switzerland. *BMC Psychiatry, 19*(1), 111. <https://doi.org/10.1186/s12888-019-2091-x>

⁶² Levitt, op. cit. note 59. p. 3.

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”.⁶³ In other words, suffering is not confined to the physical dimension but also encompasses psychological, existential, and spiritual dimensions.⁶⁴ 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 titled “Nothing hurts less than being dead”), Lengvenyte and colleagues identified several dimensions of psychological pain causing suffering in individuals who requested AD.⁶⁵ Building on the principle that the cause of suffering is irrelevant for access to AD, Schuklenk and van de Vathorst argued that “[j]urisdictions that are considering, or that have, decriminalised physician assisted dying are discriminating unfairly against patients suffering from treatment-resistant depression if they exclude such patients from the class of citizens entitled to receive assistance in dying”.⁶⁶ Consequently, we suggest that suffering caused by SPMI – even though it may be more difficult to see or to evaluate – shouldn’t be considered as less significant than the suffering caused by other illnesses and should not by itself bar the patient from access to AD.

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

⁶³ Cassell, op. cit. note 34. p. 639.

⁶⁴ Ruijs, op. cit. note 37.

⁶⁵ Lengvenyte, A., Strumila, R., Courtet, P., Kim, S. Y. H., & Olié, E. (2020). "Nothing hurts less than being dead": Psychological pain in case descriptions of psychiatric euthanasia and assisted suicide from the Netherlands. *Can J Psychiatry*.

⁶⁶ Schuklenk, U., & van de Vathorst, S. (2015). Treatment-resistant major depressive disorder and assisted dying. *J Med Ethics*. 41(8), 577–583. doi:10.1136/medethics-2014-102458. p. 577

though intolerable suffering is often inherent in the wish for hastened death, it is not sufficient as a condition to access AD, and due to its subjective nature, it cannot be fully appraised and objectively proven or disproven from the outside. Nevertheless, it remains an important concept for exploring with humility as careful and diligent as possible and trying to understand the situation 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.