

Capacity Assessments as a Safeguard for Psychiatric Patients Requesting Euthanasia

Scott Y. H. Kim MD PhD

Senior Investigator, Department of Bioethics, National Institutes of Health,
Bethesda, MD, USA.

Adjunct Professor, Department of Psychiatry, University of Michigan
Ann Arbor, MI, USA

Commentary in Response to: "Decision-Making Capacity to Consent to Medical Assistance in Dying for Persons with Mental Disorders" by Charland, Lemmens, & Wada

Can the requirement of intact decisional capacity serve as a rigorous safeguard if medically assisted death of psychiatric patients is legalized? Charland, Lemmens, and Wada present a thorough, thoughtful discussion of why the answer to this simple question is actually rather complex (Charland, Lemmens, & Wada, 2016). They fear the current means of assessing decision-making capacity cannot "bear the weight" that it is meant to bear. I think they are correct that the complexities regarding capacity assessments is underappreciated in the current policy debates on PAD (Physician Assisted Death). Thus, it may be worth further spelling out a point that has not received much attention—namely, once PAD for psychiatric disorders is legalized, the meaning of 'intact decisional capacity' will likely change from the meaning it had while legalization was being debated. To illustrate this point I offer a brief reminder about the nature of decisional capacity, after which I examine the current practice of psychiatric PAD in the Netherlands and Belgium.

The nature of capacity evaluations in the psychiatric PAD context

Decisional incapacity is not a natural phenomenon, like cancer or psoriasis or even delirium. It is a social construct used to determine whether a patient retains decisional authority when she appears to have some brain or psychological impairment. Such impairment does not always neatly and self-evidently correspond to impairments in decision-making. Someone, usually a mental health professional, must find a way to apply this constructed concept of capacity to the natural phenomena of impaired brain and psychological functioning. What prevents this determination from being arbitrary are two factors: one, the social construction of 'decisional capacity' does not go 'all the way down'—there is in fact the reality of a brain's dysfunctions; two, in most situations, there is sufficient societal agreement about *what the decision is* and *what the import of its potential consequences are* that allow interpersonal justifications of capacity judgments.

Capacity assessment is most difficult when a patient can intellectually absorb information and communicate a choice, but whose decision-making process in between is at issue. For example, a person might absorb what a doctor is describing and recommending but does not believe her because of a delusion that the doctor is actually not a doctor—a delusion that the patient will likely keep hidden (Scott Y. H. Kim). Or a person might refuse a beneficial treatment, despite seeming to absorb the relevant information, due to an unconscious fear (Jonsen, Siegler, & Winslade, 1998). Or a severely depressed but cognitively intact patient whose very ability to value anything is severely impaired (Kim, 2016). In such cases, we must use standards such as 'appreciation,' 'reasoning,' 'using or weighing information' to probe whether there is some decisional ability that is not intact. As Charland et al. note, this is a territory without clear consensus among experts and jurisdictions. It is notable, however, that psychiatric patients requesting PAD who are referred for capacity evaluations will likely show they can absorb at least some relevant information and can exhibit a preference; therefore *their capacity determination will almost always depend on those standards that are particularly difficult to assess*.

Combining these two points, one can easily see that the threshold of capacity used (the level of functioning of the relevant abilities necessary for capacity) and the parallel need to justify and document the capacity assessments will be particularly sensitive to the evaluator's understanding of "what the decision is and what the import of its potential consequences are." This is, of course, a perfectly defensible practice that is part of standard teaching: an evaluator should use a very high threshold with a clearly articulated rationale for her capacity judgment when the stakes are very high (Buchanan & Brock, 1989; Grisso & Appelbaum, 1998).

With the above background, consider two competing views of what the decision to receive PAD is and what the import of its potential consequences are.

On one understanding, human beings have an inherent worth not conditioned upon or diminished by a person's social status, gender, race, ethnicity, family origin, disease, disability, or balance of personal experiences. The society's obligation to those who endure

serious mental illness is to affirm their inherent worth by providing resources commensurate with that worth. Serious mental illnesses are not terminal illnesses. It is difficult to judge someone's mental illness "untreatable." And given that some mental illnesses can distort one's perception, thinking, and judgment, the capacity to request and receive psychiatric PAD should be assessed with a *very high threshold*—the evaluator must test for and document that the person's decisional abilities are functioning at a high level.

On another understanding, living with serious, difficult to treat mental illness is deemed to be a fate that is 'worse than death.' Given how much suffering such illnesses can cause and given the *net* benefit (eliminating experiences that are worse than death), if a person persistently asks for PAD, then there should be a benefit of doubt given to such requests. On this view, what the person is choosing seems, on balance, so rational that setting a high threshold is unnecessary.

The impact of legalization of PAD on how decisional capacity is conceptualized

It is not difficult to see which of the two understandings would become more influential in practice once PAD for psychiatric disorders is legalized. As a formal and enforceable manifestation of society's values, the law provides a powerful social endorsement. The legal uncertainty about whether psychiatric PAD is a good thing will have been settled. Over time, the medical profession will be pressured to align with these values (Kimsma, 2015; Snijdewind, van Tol, Onwuteaka-Philipsen, & Willems, 2016).

Also, as a practical matter, psychiatrically ill persons with persistent wish to die will naturally seek out and find willing doctors (even mobile clinics especially designed for PAD, if their own doctor is reluctant) (Kim, De Vries, & Peteet, 2016). After receiving PAD, they will not be able to voice an objection or a complaint. Since most psychiatric patients requesting PAD will be socially disconnected (Kim et al., 2016), their deaths may not receive much scrutiny as the post-hoc reviews will generally defer to the physicians who write the reports (Kim et al., 2016). The system will eventually have less and less reason to use very high capacity thresholds, since the system's overall goal is to make psychiatric PAD accessible as a social good.

In the jurisdictions that perform psychiatric PADs, there is evidence that, both prescriptively and empirically, high capacity thresholds are not the norm. As Charland et al note in regard to Belgian practice, the only published study shows that *none* of the 100 *consecutive* persons referred for evaluation of psychiatric PAD was found to be incompetent to make the request, despite patients having diagnoses known to increase the risk of incapacity (Thienpont et al., 2015).

In the Netherlands, the Dutch Psychiatric Association explicitly endorses the view that not all the usual criteria for capacity need to be met when "the patient is clearly suffering so unbearably..." (Tholen, 2009.). Another indication that capacity assessments for PAD need not require highest thresholds is the Dutch Euthanasia Review Committees (RTE) code of practice statement that patients in the "early stages" of dementia are usually competent to make PAD requests (Regional Euthanasia Review Committees, 2015), which seems to imply a presumption of competence. Given that

there is ample evidence that patients with even mild cognitive impairment—i.e., persons who have milder symptoms than those who actually meet criteria for dementia—have significant likelihood of decisional impairment for health decisions (Jefferson et al., 2008; Okonkwo et al., 2007), this seems to be another indication that when it comes to PAD requests, the Dutch system does not require that capacity thresholds be very high.

In Dutch practice, an examination of the case summaries written by the RTEs reveal that in 55% (36/66) of cases, there are only simple global assertions of capacity ("...the patient was mentally competent"), even though 22% of them had psychotic conditions (Doernberg, Peteet, & Kim). Only about a third of the case reports (21 of 66) provided specific evidence in support of or against at least one capacity-specific ability. In 8 cases there was disagreement about the patient's capacity among the physicians involved; in 4 of those cases, the RTE does not comment on the disagreement or request any further information from involved physicians (Doernberg et al.).

Even when physicians did agree, the details of their agreement were sometimes surprising. For example, in a case of a woman in her 70s with severe personality disorder, multiple suicide attempts, mental retardation, and psychotic symptoms, two physicians agreed that the patient possessed intact capacity. The first physician appealed especially to her ability to "weigh pros and cons" as evidence of intact capacity. The second physician, however, specifically noted that the patient's ability to "use information in a rational way was doubtful." *In effect, the two physicians agreed on the outcome but with contradictory reasoning.* The review committee did not address this discrepancy (Doernberg et al.).

Conclusions

The hope that we can protect psychiatric patients sufficiently by imposing a strict system of safeguards is based on a perspective prior to legalization of psychiatric PAD. But we fail to note that *the legalization itself will likely change the social and practice context* of how the safeguards are applied. The very act of legalizing psychiatric PAD provides strong support for it as a social good; this then becomes the context for capacity determinations and the idea of a strict capacity threshold will begin to seem unnecessary, even obstructive. This is not a claim about a slippery slope of abuses and errors; the point is that the very norm of what an abuse or an error means will be recalibrated to the new reality, an apparently reassuring reality (Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016) with no evidence of abuses and errors.

References

- Buchanan, A. E., & Brock, D. W. (1989). *Deciding for others: the ethics of surrogate decision making*. New York: Cambridge University Press.
- Charland, L. C., Lemmens, T., & Wada, K. (2016). Decision-Making Capacity to Consent to Medical Assistance in Dying for Persons with Mental Disorders. *Journal of Ethics in Mental Health, Open Volume*, 1-14.

- Doernberg, S. N., Peteet, J. R., & Kim, S. Y. H. (in press.). Capacity Evaluations of Psychiatric Patients Requesting Assisted Death in the Netherlands. *Psychosomatics*. doi: 10.1016/j.psych.2016.06.005
- 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
- Grisso, T., & Appelbaum, P. S. (1998). *Assessing competence to consent to treatment: A guide for physicians and other health professionals*. London: Oxford University Press.
- Jefferson, A. L., Lambe, S., Moser, D. J., Byerly, L. K., Ozonoff, A., & Karlawish, J. H. (2008). Decisional capacity for research participation in individuals with mild cognitive impairment. *J Am Geriatr Soc*, 56(7), 1236-1243.
- Jonsen, A. R., Siegler, M., & Winslade, W. (1998). *Clinical Ethics*. New York: McGraw-Hill.
- Kim, S. Y. H. (2010). *Evaluation of Capacity to Consent to Treatment and Research*. New York: Oxford University Press.
- Kim, S. Y. H. (2016). The Place of Ability to Value in the Evaluation of Decision-Making Capacity. In D. Moseley & G. Gala (Eds.), *Philosophy and Psychiatry: Problems, Intersections and New Perspectives*. New York: Routledge.
- Kim, S. Y. H., 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
- Kimsma, G. K. (2015). Longevity reversed: Medicine, suicide and laicide after the Euthanasia Law of 2002. *Ethics, Medicine and Public Health*, 1(2), 220-229. doi: <http://dx.doi.org/10.1016/j.jemep.2015.04.008>
- Okonkwo, O., Griffith, H. R., Belue, K., Lanza, S., Zamrini, E. Y., Harrell, L. E., . . . Marson, D. C. (2007). Medical decision-making capacity in patients with mild cognitive impairment. *Neurology*, 69(15), 1528-1535.
- Regional Euthanasia Review Committees (Regionale toetsingscommissies euthanasie, o. R. (Published April 2015, Accessed October 30, 2015). *Code of Practice*. The Hague, the Netherlands.
- Snijdewind, M. C., van Tol, D. G., Onwuteaka-Philipsen, B. D., & Willems, D. L. (2016). Developments in the practice of physician-assisted dying: perceptions of physicians who had experience with complex cases. *Journal of Medical Ethics*. doi: 10.1136/medethics-2016-103405
- Thienpont, L., Verhofstadt, M., Van Loon, T., Distelmans, W., Audenaert, K., & De Deyn, P. P. (2015). Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study. *BMJ Open*, 5(7). doi: 10.1136/bmjopen-2014-007454
- Tholen A, B. R., Huisman J, et al. (2009.). Richtlijn omgaan met het verzoek om hulp bij zelfdoding door patiënten met een psychiatrische stoornis (Directive dealing with the request for assisted suicide by patients with a psychiatric disorder). *Utrecht: Nederlandse Vereniging voor Psychiatrie*.

Please note: The opinions expressed in this commentary are the author's and do not represent the views of the NIH, Department of Health and Human Services, or the U.S. government.

Acknowledgments: The author thanks Frank Miller, Ray De Vries, and Louis Charland for comments on an earlier draft.

Competing Interests: None

Address for Correspondence:

e-mail: scott.kim@nih.gov

Date of Publication: December 2 2016