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Peer Reviewed

Euthanasia in Mental Illness: A Four Part Series

Part III: Capacity to Consent

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Abstract

The ability to consent arises forcibly when the medical intervention requested is euthanasia which guarantees death. Here, the bar to establish capacity to consent must be as high as possible and becomes very complex where mental illness is the reason for the request, as mental illness necessarily involves a disturbance in normal mental functioning. Four psychobehavioral elements are needed to establish capacity to consent. The patient must be able to communicate a choice; understand the relevant information; reason about treatment options; and appreciate their situation and its consequences. To appreciate their situation and its consequences is the strictest standard of evidence for capacity. In mentally ill patients unbearable suffering, which arises from pathological illness based sadness, distorts normal cognitive operations, and undermines and invalidates the ability to appreciate. Without this ability, mentally ill patients cannot be deemed to be competent to consent to euthanasia.

Keywords: Capacity, consent, euthanasia

Treatments in medicine often have risks. Patients must be informed and provide consent to proceed. Where the risk is low or inconsequential, as with nausea that will disappear with the cessation of the medication, consents are often implied such as the acceptance of a prescription for the treatment of hypertension. Where the risks are high and consequential, such as with invasive or surgical interventions, the patient's consent needs to be documented in writing.

The issue of the ability to provide consent (capacity to consent) only comes into question when there

are concerns about a disturbance in brain functioning that is disrupting the patient's ability to process information and to make well-reasoned decisions. Here, the physician must confirm that the patient has the capacity to provide consent if the consent is to be valid.

For terminological clarification, capacity and competency are often used interchangeably, but this is incorrect. Capacity denotes a clinical status as judged by the health care professional, whereas competency denotes a legal status as judged by a legal professional, such as a judge (Marson, 2001).

Capacity assessment is task specific. The normal adult has distinct and multiple capacities including the capacity to make a will, to drive, to consent to medical treatment, to manage her or his financial affairs and, ultimately, to manage her or his personal affairs. Each of these capacities involves a distinct combination of functional abilities and skills that sets it apart from other capacities (Marson, 2001).

In the case of a request for medical assistance in suicide (MAIS), we need to establish only the capacity to consent to the medical treatment under consideration. However, we are dealing with a patient with a psychiatric disorder and this necessarily involves a disturbance in normal mental functioning. Here, the capacity to provide consent arises forcibly and, given the gravity and irreversibility of the intervention under consideration, the bar for capacity has to be set at the highest possible level.

Four psychobehavioral elements must be demonstrated to be present to establish capacity (Appelbaum & Roth, 1982; Appelbaum & Grisso, 1995; Appelbaum 2007):

1. Communicate a choice: The patient must clearly be able to indicate a preferred treatment option. This is the least rigorous standard of evidence and the easiest to document. It is usually completed by having the patient sign a consent form that indicates agreement to the treatment and that the

material risks were discussed. Ideally, these should be listed on the consent form.

2. Understand the relevant information**:** The patient must understand the relevant information and fundamental meaning of information communicated by the physician as it exists in the abstract. They must show that they know that a given medical condition exists, that there are treatment options with risks and benefits, and the possible outcomes without treatment.

3. Reason about treatment options: The patient must be able to engage in a rational process of manipulating the relevant information or reason with relevant information so as to engage in a logical process of weighing options. This will involve demonstrating the integrity of the patients' computational capacities (neurocognitive abilities) via simple bedside testing such as the Mini Mental Status Examination (Folstein, Folstein, & McHugh, 1975) or more complex extensive formal neuropsychological testing and confirming the absence of any florid psychopathology that would compromise these capacities.

4. Appreciate their situation and its consequences: The patient must acknowledge that they have a medical condition, the likely consequences of treatment options, and that these are applicable to their own circumstance. This is the strictest standard of evidence of capacity. According to Appelbaum and Grisso (1995), a patient who understands that their physician believes they are ill but in the face of objective evidence to the contrary, deny that this is so or who understands that an effective treatment exists but refuse to believe that it is likely to help them, will be said to lack appreciation.

Psychiatric conditions that undermine appreciation include florid psychosis where voices, visions, inserted thoughts, delusional beliefs, nihilistic depression, or executive capacity failure due to frontal lobe injury have seized control of or undermined the patient's sense of agency and now are the predominant decision making mechanism, pathologically distorting rational choice making and the ability to make prudent self preserving judgements. Here, the confounding neurocognitive deficits and psychopathology are obvious to others but not to the patients themselves.

Falling under the concept of "appreciate" is the awareness about how others may see and judge

their behaviour and responses, and reflects the ability to self monitor and know whether their behaviour falls within the range of "normal range responses" for a given situation.

This lack of insight is one of the most complex and frightening aspects of mental illness (Appelbaum & Roth, 1982; Appelbaum 2007). While in this disordered state of mind, the patients' behavior and responses seem to them to be entirely rational and normal, or the risks to themselves denied, minimized, or rationalized. This insight, if it occurs, will only take place in hindsight when the illness has passed. To others, however, these behaviours are textbook symptoms of a disabled mind. In psychosis or mania, the lack of insight is totally obvious. In psychosis, patients have no idea that the voices and visions that they are hearing and seeing are a result of a brain illness. They respond to them as truly happening, just as you and I would respond to the sight and the voice of a friend who suddenly appeared. In mania, they may believe that they are mankind's now revealed savior and start preaching at the local mall, having given away all their earthly possessions. The lack of insight is more subtle in depression, where the patients may experience and complain of suicidal thoughts and impulses but do not believe themselves to be at serious risk, telling no one or having told the emergency room doctor about their self-destructive impulse, refuse treatment and want to go home, only to kill themselves if no one steps in to save them from themselves.

The nature of rationality itself is also complex. "Normal" human decision-making is not mathematically logical. Humans are not electromechanical statistical calculators. There is general consensus that emotions play an essential role in decisions and judgments, and this is often done unconsciously (Clore & Huntsinger, 2007; Lerner et al., 2013, 2015). Affective as well as other cognitive heuristics (rules of thumb) and biases are at work all the time. A highly robust example is that when faced with catastrophic and total loss, normal "rational" humans will take large risks even for the smallest chance to avoid this outcome (Kahneman, 2011). This normal "loss aversion" appears to be inverted in depressive illness because an extraordinary emotional bias is at work. The mind is ill and has generated a pathological sadness, depressive illnesses' defining symptom. The depressed patient wants to die – a total loss of all and everything because pathological psychache makes suicide seem to be the only "rational" way to escape the pain.

All humans, including those that are depressed, should be willing to try everything to avoid total loss even if the chance of success is small. This is the rational thing to do.

The above principles always apply without exception when dealing with acutely depressed patients. Suicidality is the hallmark of a mental illness and, in particular, depression. In the acute setting and at first presentation, there is never any doubt that the patient's suicidality is a function of her or his depression and the self-destructive impulses are emerging directly out of this mental disturbance. There is no mental health professional who would consider suicidality a rational conclusion. Suicidality is the product of a diseased mind, a mind in pain, a mind that is not under the patient's control, and it is this diseased mind that is putting the patient's life at risk. The mental health professional is expected to protect and then treat the patient. Failing to do so would be considered negligence. If the patient will not accept treatment and cannot be managed safely in the community, then that patient will be hospitalized and treated against her or his will.

Most, if not all, of these treatment-refusing patients will be found to possess the first 3 standards of capacity, namely: the ability to provide consent, to grasp the fundamental facts of the problem, and to show the ability to utilize logic. Where they fail the test of capacity is in the ability to appreciate. They will fall into that category of patients who understand that their physicians believe they are ill but deny that this is so, or who understand that they are ill and at risk of self-harm and that effective treatment exists but refuse to believe that it is likely to help them, or to acknowledge that if untreated, they are at real risk of killing themselves and that they need protection and treatment. They are failing to acknowledge a medical condition and the likely consequences of treatment or lack thereof which is applicable to their own circumstance.

The timeframe now shifts; 5-10 years later, this same patient remains severely depressed despite multiple trials of various antidepressants, counseling and psychotherapy, and two or more courses of electroconvulsive therapy (ECT). Suicidal ideation persists and the patient decides that the only

way to terminate the psychache is to be dead. They want no more treatment. They do not believe that any treatment alternatives (psychosocial and biological) will change the magnitude of their suffering. The future seems hopeless and only filled with unbearable psychache. They now present their suicidal ideation as an understandable, reasonable, and well-reasoned decision, given their circumstances. They want to implement their suicidal wishes but want a dignified, peaceful and guaranteed death. They now request medical assistance to implement this decision.

But in fact, there are alternative treatments. Their psychosocial circumstances are modifiable. They can be provided with more counseling, psychotherapy, and community support. Different antidepressants, antidepressant combinations, other medications, another course of ECT followed by maintenance ECT, are immediately available. New antidepressants have become available. Deep brain stimulation is under investigation and the results look promising. These may not cure the psychache but with persistence will provide sufficient alleviation to make life worth living. If their response still remains suboptimal, they may be eligible and qualify for limbic surgery.

The patient disputes all of this. Their thinking is clear and rational. They have lived with this condition for 5-10 years and they have had enough. They have come to this conclusion after deep introspection. It is logical and rational and anyone in their particular situation would come to the same conclusion. They dispute the fact that psychache from ongoing depression has not only distorted their decision-making processes but is also the reason for their hopelessness and declining further treatment.

They do not believe that any treatment options would be helpful. They do not see that you and others would see that there is still room for hope, even in their particular case. They do not believe you when you tell them that psychache can be attenuated. In any case, they have had enough. They know that most other patients with chronic severe depression would not and do not give up but will seek any treatment that may offer a hope of improvement, all with the wish to stay alive. This does not apply to them. Their situation is unique. They have given up and this is logical and rational. They want to be dead and only want one treatment, and that is medical help with their suicide.

I would submit that such individuals lack appreciation of their situation. They understand with varying degrees of insight that psychache is the cause of their suicidal ideation but they do not see that it is also distorting their thinking, and if told, would dispute this. They cannot see that psychache is making them feel so hopeless that they discount the possibility of benefitting from any other psychosocial and biological treatment or even the option of limbic surgery, if this intervention will save their life. They do not want to be saved. This may apply to others but does not apply to them.

Is there any evidence that psychache from a diseased mind is central to this problem and is responsible for the suicidal ideation, hopelessness, and unwillingness to pursue further treatment? Is there any evidence that in the presence of psychache, the patient's thinking is irrational?

What would happen if psychache could be removed? Would the patient think and behave otherwise, and only when looking back recognize that their thinking was irrational and that in the midst of chronic severe depression, they could not appreciate this regardless of feedback to the contrary?

Our experience with capsulotomy provides such empiric data (Hurwitz et al., 2012). As already set out in part II, the most striking effect of bilateral anterior capsulotomy (BAC) is its tristolytic effect. This dramatic effect is seen in the first 1-2 weeks post-BAC, when clarity of thinking and the capacity to introspect returns.

It is worthwhile to reflect upon what has transpired here. Sadness, and with it, suicidality, have settled with no other changes in the patients' psychosocial circumstances and no changes in their medications. Surgery has seemingly worked solely by eliminating a critical biological disturbance within the brain and done by severing a malfunctioning brain pathway. Other psychosocial stressors may be contributing but are peripheral.

The patients' thinking is "instantly" altered by surgery; these patients have been suicidal for years. To qualify for this procedure, patients must have for been ill for at least 5 years and must have tried all other biological and psychological interventions. Most patients have been ill for longer than 5 years. Their neurocognitive abilities with which they can reason, think, and compute are preserved. All patients undergo formal neuropsychological assessment before, at 2 months, and at 1 year after surgery. The vast majority of neuropsychological domains are either unchanged or improved (Hurwitz, 2012). The fundamental computational and decisional capacities of their brains has remained and continues to remain intact. All that has happened is that pathological sadness has been taken out of the cognitive equation. Sadness is the very illness itself. It was the cause of suicidal ideation in the acute setting and remains the cause in the chronic setting. They were mentally ill then and remain mentally ill now. To be risk averse is normally "rational". To want death is irrational, and rationality is instantly restored when the illness-based affective bias is removed.

This tristolytic and anti-suicidal effect has persisted in most patients for more than 10 years in those patients that I have followed for this duration. Seventeen years after capsulotomy, one of my patients reported the following when asked her to reflect upon her depressive illness. Her depression had started in her teens; she was suicidal because she wanted to end the pain; she cut herself because "physical pain was easier to deal with than psychic pain"; she recalls the many times that she had a rope around her neck, wanting to jump off a building but knowing that she actually wanted to live. The surgery "saved my life". The major benefit of surgery was that it "took away the pain".

Depressed patients, whether acutely or chronically ill and who want to suicide, lack appreciation of their situation. In proclaiming their rationality, they reveal their lack of appreciation and the presence of an ongoing active life-threatening mental illness. They fail to meet the test of capacity to consent to a medical procedure that would terminate their lives.

References

Appelbaum, P. S. (2007). Clinical practice. assessment of patients' competence to consent to treatment. *The New England Journal of Medicine, 357*(18), 1834-1840.

Appelbaum, P. S., & Grisso, T. (1995). The MacArthur treatment competence study. I: Mental illness and competence to consent to treatment. *Law and Human Behavior, 19*(2), 105-126.

Appelbaum, P. S., & Roth, L. H. (1982). Competency to consent to research: A psychiatric overview. *Archives of General Psychiatry, 39*(8), 951-958.

Clore, G. L., & Huntsinger, J. R. (2007). How emotions inform judgment and regulate thought. *Trends in Cognitive Sciences, 11*(9), 393-399.

Folstein, M. F., Folstein, S. E. & McHugh P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. *12*(3),189-98.

Hurwitz, T. A., Honey, C. R., Allen, J., Gosselin, C., Hewko, R., Martzke, J., et al. (2012). Bilateral anterior capsulotomy for intractable depression. *The Journal of Neuropsychiatry and Clinical Neurosciences, 24*(2), 176-182.

Kahneman, D. (2011). Thinking, Fast and Slow. New York (NY): Farrar, Straus and Giroux.

Lerner, J. S., Li, Y., Valdesolo, P., & Kassam, K. S. (2015). Emotion and decision making. *Annual Review of Psychology, 66*, 799-823.

Lerner, J. S., Li, Y., & Weber, E. U. (2013). The financial costs of sadness. *Psychological Science, 24*(1), 72-79.

Marson, D. C. (2001). Loss of competency in Alzheimer's disease: Conceptual and psychometric approaches. *International Journal of Law and Psychiatry, 24*(2-3), 267-283.

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