

Live or Let Die: Ethical Issues in a Psychiatric Patient with End-stage Renal Failure

Aaron Ang,¹MBBS, MMed (Psychiatry), MRCP (Int Med), Peter CW Loke,²MB, BCh BAO, LLB, Alastair V Campbell,³MA, BD, ThD, Siow Ann Chong,⁴MBBS, MMed (Psychiatry), FAMS

Abstract

Medical co-morbidities are very common in patients with psychiatric conditions. Although respecting one's autonomy to make treatment decisions is the ethical default position, the capacity to make such decisions may need to be assessed, especially when patients are in relapse of their psychiatric condition, and/or when the decisions made are high-risk and possibly fatal. This case report highlights the ethical issues of refusing potential life-saving treatment in a patient who is in relapse of her schizoaffective disorder. In particular, the assessment of decisional capacity and the role of the doctors (if the patient lacks capacity) are discussed. Recommendations are also made on how to better manage such situations.

Ann Acad Med Singapore 2009;38:370-3

Key words: Autonomy, Best-interests standard, Mental capacity

Case Report

Ms T was a single, 41-year-old Chinese female who had been diagnosed with schizoaffective disorder at the age of 21. Her illness was characterised by frequent relapses and admissions to hospital; the longest admission was for more than a year when she was 27 years old.

During her periods of relapse, her mood was elevated; she was talkative, irritable and had grandiose delusions. There were episodes of overspending and thought disorder as well as auditory hallucinations during her admissions. The main reason for her relapses was non-compliance to medication from a lack of insight to her mental illness as well as from medication-induced side effects.

There were 2 sustained periods in her 20-year history when she was well enough to work. The first was between 31 to 34 years old when she worked as a hotel clerk, and the second was just before the diagnosis of end-stage renal failure when she was a private tutor. At that time, she was 39 years old.

Ms T, who was hypertensive, developed end-stage renal failure when she was 40 years old. She had initially refused to undergo dialysis but after some persuasion, she consented to it. During the course of preparing her for dialysis, she was referred on 2 separate occasions for assessment by a psychiatrist in the general hospital where she was being

treated for renal failure. The opinions on these 2 occasions were that she was not fit to either give or refuse consent for dialysis and that her abnormal mental state could be further alleviated with treatment. Throughout this period, she had expressed ambivalence towards dialysis.

She subsequently defaulted both medical and psychiatric treatment for 2 weeks before landing up at the emergency department of the general hospital in a state of relapse of her psychiatric illness. During that hospital admission, she refused all forms of treatment including dialysis and had pulled out all her intravenous access. As her physical condition deteriorated, discussions were held with the family and the family elected for conservative management. She was not dialysed and died 2 days later.

Discussion

This case raises a number of issues: autonomy of a patient with regard to medical treatment, assessment of the patient's decisional capacity, and the process of deciding on the appropriate course to take in a patient without the mental capacity to give consent for required treatment in a potentially life-threatening situation.

Autonomy can be defined as the quality or state of being independent, free and self-directing. It is generally accepted that the respect for one's autonomy is the ethical default position. The fundamental premise for autonomy to make

¹ Department of Geriatric Psychiatry, Institute of Mental Health, Singapore

² Syngenta Asia Pacific Pte Ltd and Adjunct Lecturer, Yong Loo Lin School of Medicine, National University of Singapore, Singapore

³ Chen Su Lan Centennial Professor of Medical Ethics, Yong Loo Lin School of Medicine, National University of Singapore, Singapore

⁴ Institute of Mental Health, Singapore

Address for Correspondence: Dr Aaron Ang, Institute of Mental Health, Buangkok Green Medical Park, 10 Buangkok View, Singapore 539747.

Email: Aaron_Ang@imh.com.sg

an informed consent is dependent on an intact decisional capacity. Decisional capacity is a cognitive ability and has the following components: understanding the information relevant to the decision, appreciating the information, applying the information to one's situation (using the information in reasoning), and being able to express a choice.^{1,2} Therefore, regardless of his medical or psychiatric condition, a person will have the capacity to participate in informed consent provided he is able to understand the nature and purpose of a treatment option. In the instance where a person's decisional capacity is challenged, the court is the final arbitrator, but it will base its decision on the available medical evidence. Assessment of this decisional capacity is entrusted to the physicians. Unfortunately, there is no consensus on how this should be done, resulting in a "hodge-podge of practices".³

This decisional capacity can be potentially compromised in certain conditions such as cognitive impairment, and psychiatric conditions such as depression and psychosis.⁴ ⁶Situational factors such as the complexity of information disclosed and the manner in which it is disclosed may also reduce one's decisional capacity.

In conditions such as schizophrenia and other disorders including schizoaffective disorder, the patient's ability to fully participate in the decision-making process may be chronically impaired and the degree of impairment may vary over time.⁷⁻¹¹

The assessment of the patient's decisional capacity may be compounded by the fact that in different contexts, there may be demands for different levels of functional abilities. Therefore, in the case of a lower risk treatment, a lower level of decisional capacity is required as compared to a high-risk treatment.^{1,12-17}

The concept of chronic and variable impaired autonomy has a few important implications – there is the possibility of improvement of one's decisional capacity with the treatment of the primary disorders, using strategies such as education and psychosocial interventions. It also raises the issue of the non-consensual treatment of a mentally unwell patient who refused treatment. This has been discussed by Appelbaum¹⁸ from the judicial perspective and falls into 2 approaches: rights-driven or treatment-driven. The basis of the former approach is that "all competent persons have the right to control intrusions into their bodies".¹⁸ The emphasis is on being "competent" and is not the mental illness itself. In the treatment-driven approach, the decision to initiate treatment is left to the attending physician who is presumed to "know better" than anyone else what treatment the patient requires – "a physician's determination that treatment was needed was sufficient to justify its administration, regardless of patient's wishes."¹⁸

The UK Mental Capacity Act (2005) has safeguards against the abuse of implementing treatment on those thought to lack capacity. It states that before implementing the treatment or procedure, the doctor must take reasonable steps to establish that the patient lacks capacity and that the treatment or procedure is in the best interest of the patient (the best interests standard is discussed later). Clinically, the inclusion of an independent clinical review to assess the appropriateness of the treatment to be administered is a variation of this approach. Ideally, judicial assent should be obtained. However, in the most dire of emergencies, it would be the physician who would have to make a judgment based on the above principles.

The Ulysses contract is an option worth considering where a patient, in relapse of her mental illness, reverses her decision for treatment because of her abnormal mental state. In the Iliad, Ulysses had longed to hear the Siren's song but was aware that he would be overwhelmed by their song and would lose the capacity to make appropriate choices. To overcome this conundrum, he instructed his crew to block up their ears and tie him to the mast. His orders were to not release him from the mast until they were out of earshot of the Sirens. Ulysses tied to the mast has become the paradigm example of this phenomenon in ethical literature.¹⁹ It is argued that such a declaration, made when the patient is in remission of his mental illness, would be when his decisional capacity is relatively unimpaired. Decisions made at that point would therefore, avoid the risk of consent taken when the patient is in a state of relapse, when the decisional capacity would be more severely impaired.²⁰ The "Ulysses contract" would help guide the patient's treatment choices when he is in relapse of the mental illness, therefore allowing decisions to be made in keeping with the patient's values and preferences. Ulysses contracts are reversible and, at this point in time, not legally binding. It is therefore the responsibility of the clinician, when entering into the Ulysses contract, to assume that the patient has adequate decisional capacity. The contract does not function to protect autonomy, but to assist in reminding the patient of her earlier stated preference in an attempt to enhance her decisional capacity²¹ as well as to serve as a guide that will address her deepest identity conferring concerns.²²

In the United States, the Patient Self-Determination Act guarantees patients the right to formally designate a surrogate to make treatment decisions for them if they become unable to make their own decisions.²³ In the event that such a declaration is not made, most states have statutes to identify a next-of-kin surrogate for them.²⁴ Patient-designated or next-of-kin surrogates are instructed to make their decisions based on 1 of 2 standards: substitute judgment standard or best interests standard.

The substitute judgment standard involves making the treatment decision that the patient would have made if he or she were not incapacitated.^{25,26} This presumes that the surrogate has a close and intimate relationship with the patient such that he would have sufficient evidence to determine what decision the patient would have made. Proponents for the use of the substitute judgment standard argue that this allows for patients' preferences and values to guide decisions on their treatments, even after they lose their decisional capacity. However, this is fraught with some difficulties. The accuracy of surrogate decisions has often been called into question. Indeed, commentators argue that surrogate decisions are frequently inaccurate²⁷ and are in disagreement with patients' preferences.²⁸ Others have even said that it is "no better than chance" at predicting the decisions of patients when they were capacitated.²⁹ A recent systematic review of the literature showed that overall, surrogates predicted patient's treatment preferences with 68% accuracy.³⁰ This was regardless of whether it was a patient-designated or next-of-kin surrogate.

There are many reasons why decisions made by patient-designated or next-of-kin surrogate may be inaccurate. The surrogate decision-maker will invariably bring his or her judgment into the decision-making process. Especially in the case of chronic illness, where caregiver burden and financial expenses are significant, such concerns may colour their judgment and hence call into question whether the decisions were indeed in the best-interests of the patient. On the other hand, it may also be unfair for the family to have to make such difficult (life-and-death) decisions as they may be very emotional at that point in time. Moreover, they are not medically trained and may not fully appreciate the various options available (in spite of repeat and simplified explanations). In these instances, the family's decision may fall below the minimum standard of acceptable care and/or is in conflict with the physician's recommendations. The alternative is the best interests standard, which was initially introduced to safeguard the interest of incapacitated patients independent of the views of their guardians, so that a minimum standard of care would be maintained.³¹

In such instances, the medical decision (for an incapacitated patient) usually falls on the shoulders of the treating physician, who should use the best interests standard. A recent study in the US on the decision to limit life-sustaining treatment in critically ill patients also reflects this trend.³² In this study, it was found that 16% of patients admitted to medical ICU lacked decision-making capacity as well as a surrogate decision-maker. The decision to limit life support was generally made by physicians – often in consultation with the family. The family's wishes are often a crucial deciding factor in the real world. Fear of complaints

by the family and possible litigation may cloud the physician's judgment, who may lapse into the practice of "defensive medicine" or treatments that are perceived to most likely "avoid litigation" even when they are not strictly warranted, and may be unnecessarily expensive and time-consuming, but more importantly, not in the best interest of the patient (for example, intubating a terminally ill patient at the family's insistence for fear of litigation). On the contrary, failure to act in the best interests of the patient is, in fact, not a legally supported position.

The above discussion is important and relevant as Singapore has passed its Mental Capacity Act in 2008 (author to pls rephrase this sentence). The new legislation, which mirrors closely the UK Mental Capacity Act (2005), aims to provide a legal framework to assess mental capacity, to safeguard the rights and well-being of the incapacitated patient, as well as to protect both the formal and informal caregiver against litigation, when he or she acts in the best interest of the incapacitated patient.

The UK Mental Capacity Act (2005) and its proposed Singapore counterpart sets out the guidelines for determining the best interests standard. In applying this standard, it should not be based merely on the patient's age, appearance, illness or behaviour. Rather, it should consider whether the incapacity is temporary or permanent, and if it is temporary, when the patient will regain capacity. Where reasonably practicable, the patient should be allowed to participate in the decision-making process. His beliefs and values, past and present wishes and feelings should be taken into account and the process should involve discussions with carers, next of kin, and persons named by the patient or the courts (if previously appointed to have lasting power of attorney over the patient). The best interests standard should seek the best available care for the incapacitated person, which includes careful attention to comfort care and pain control, but need not necessarily mean an extension of biological life.³³ It should strive for the ideal while at the same time, be grounded in what is practical and reasonable.³⁴ Therefore, it also does not require doctors making the decision to disregard their other duties, such as the allocation of scarce resources. It requires the doctor to use the best available information to assess immediate and long-term benefits, make choices that are at least meeting the minimum threshold of acceptable care and such choices should be compatible with the moral and legal duty to the incompetent patient.

Recommendations for Clinical Practice

In a patient with a mental illness which can cause fluctuating decisional capacity, a number of options could be explored, from the use of an Ulysses contract, to the appointment of a surrogate decision-maker at the point

when the patient is mentally capable, educating these surrogates on the key aspects of substituted judgment and best interests standard. This would also require the best available information needed to assess immediate and long-term benefits. The best available information can easily be compromised by miscommunication, conflicts of interest, bias and prejudice. Therefore, to get the best available information, it is essential that there be good communication between all clinicians involved especially when a patient has multiple illnesses with multiple professional carers.

There should be protocols for mentally ill patients who refuse medications to provide adequate safeguards for the rights and welfare of patients, and oversight for non-consensual treatment. Unfortunately, as mentioned previously, there is no consensus on how decisional capacity should be assessed. In the domain of clinical research, over 20 clinical structured assessment instruments have been used for assessing decisional capacity. A recent review article³⁵ suggests that the MacArthurs Competent Assessment Tools for Clinical Research and Treatment (MacCAT-CR) has the most empirical support. The use of a widely validated assessment tool, such as this, may be the next step forward in standardising the assessment of decisional capacity. However, at this point in time, all these instruments vary in reliability and validity as well as suffer from limitations. Therefore, in the words of the Council on Bioethics (which advises the President of the United States on ethical issues related to advances in biomedical science and research), “in the end no legal instrument can substitute for wise and loving choices, made on the spot when the precise treatment dilemma is clear and care decisions are needed”.³³ To be ready for this, clinicians must understand their responsibilities, be prepared to act ethically and compassionately, and apply both medical and moral principles to help their patients.

REFERENCES

- Roth LH, Meisel A, Lindz CW. Test of competency to consent to treatment. *Am J Psychiatry* 1977;134:279-84.
- Grisso T, Appelbaum PS. *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. New York: Oxford University Press, 1998.
- Michels R. Research on persons with impaired decisional capacity making and the public trust (editorial). *Am J Psychiatry* 2004;162:777-9.
- Dunn LB, Jeste DV. Enhancing informed consent for research and treatment. *Neuropharmacology* 2001;24:595-607.
- Wirshing DA, Wirshing WC, Marder SR, Liberman RP, Mintz J. Informed consent: assessment of comprehension. *Am J Psychiatry* 1998;155:1508-11.
- Roberts LW. Informed consent and the capacity for voluntarism. *Am J Psychiatry* 2002;159:705-12.
- McCullough LB, Coverdale JH, Bayer T, Chervenak FA. Ethically justified guidelines for family planning interventions to prevent pregnancy with female chronic mental patients. *Am J Obstet Gynaecol* 1992;167:19-25.
- McCullough LB, Coverdale JH, Chervenak FA. Ethical challenges of decision making with pregnant patients who have schizophrenia. *Am J Obstet Gynaecol* 2002;187:696-702.
- Coverdale JH, Bayer TL, McCullough LB, Chervenak FA. Respecting the autonomy of chronic mentally ill women in decisions about contraception. *Hosp Community Psychiatry* 1993;44:671-4.
- Coverdale JH, Chervenak FA, McCullough LB, Bayer T. Ethically justified clinical comprehensive guidelines for the management of the depressed pregnant patient. *Am J Obstet Gynaecol* 1996;171:169-73.
- Coverdale JH, McCullough LB, Chervenak FA, Bayer TL, Weeks S. Clinical Implications of respect for autonomy in the psychiatric treatment of pregnant patients with depression. *Psychiatr Serv* 1997;48:209-12.
- Appelbaum PS, Grisso T. *MacCAT-CR: MacArthur Competence Assessment Tool for Clinical Research*. Sarasota, Fla: Professional Resource Press, 2001.
- Drane JF. Competency to give an informed consent: a model for making clinical assessments. *JAMA* 1984;252:925-7.
- Kim SYH, Karlawish JHT, Caine ED. Current state of research on decision-making competence of cognitively impaired elderly persons. *Am J Geriatr Psychiatry* 2002;10:151-65.
- Grisso T. *Evaluating Competencies: Forensic Assessments and Instruments*. 2nd ed. New York: Kluwer Academic/Plenum, 2003.
- Kapp MB, Mossman D. Measuring decisional capacity: cautions of the construction of a “capacimeter.” *Psychol Public Policy Law* 1996;2:73-95.
- Glass KC. Refining definitions and devising instruments: two decades of assessing mental competence. *Int J Law Psychiatry* 1997;20:5-33.
- Appelbaum PS. The right to refuse treatment with antipsychotic medications: retrospect and prospect. *Am J Psychiatry* 1988;145:413-9.
- Dworkin G. *The Theory and Practice of Autonomy*. Cambridge: Cambridge University Press, 1998.
- Winston ME, Winston SM, Appelbaum PJ, Rhoden NK. Can a subject consent to a “Ulysses Contract”? *Hastings Cent Rep* 1982;12:26-8.
- Coverdale JH, McCullough LB, Chervenak FA. Assisted and surrogate decision making for pregnant patients who have schizophrenia. *Schizophr Bull* 2004;30:659-64.
- Van Willigenburg T, Delaere PJJ. Protecting autonomy as authenticity using Ulysses contracts. *J Med Philos* 2005;30:395-409.
- Patient Self Determination Act of 1990. Available at: www.fha.org/acrobat/Patient%20Self%20Determination%20Act201990.pdf. Accessed January 2006.
- Sabatino CP. The legal and functional status of the medical proxy: suggestions for statutory reform. *J Law Med Ethics* 1999;27:52-68.
- Buchanan AE, Brock DW. *Deciding For Others: The Ethic of Surrogate Decision Making*. Cambridge: Cambridge University Press, 1989.
- Emanuel EJ, Emanuel LL. Proxy decision making for incompetent patients: an ethical and empirical analysis. *JAMA* 1992;267:2067-71.
- Fagarel A, Ditto PH, Danks JH, Houts RM, Smucker WD. Projection in surrogate decisions about life-sustaining treatments. *Health Psychol* 2001;20:166-75.
- Ouslander JG, Tymchuk AJ, Rahbar B. Health care decisions amongst elderly long-term care residents and their potential proxies. *Arch Intern Med* 1989;149:1367-72.
- Principe-Rodríguez K, Rodríguez-Cintrón W, Torres-Palacios A, Casal-Hidalgo J. Substituted judgment: should life-support decisions be made by surrogate? *P R Health Sci J* 1999;18:405-9.
- Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med* 2006;166:493-7.
- Krause HD. *Family Law in a Nutshell*. 2nd ed. St Paul: West Publishing Co, 1986.
- White DB, Curtis JR, Lo B, Luce JM. Decision to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Crit Care Med* 2006;34:2053-9.
- President’s Council on bioethics. Taking care: Ethical caregiving in our aging society. Presentation at the President’s Council. Washington DC, 2005.
- Kopelman LM. The best interests standards for incompetent or incapacitated persons of all ages. *J Law Med Ethics* 2007;35:187-96.
- Dunn LB, Nowrangi MA, Palmer BW, Jeste DV, Saks ER. Assessing decisional capacity for clinical research and treatment: A review of instruments. *Am J Psychiatry* 2006;163:1323-34.