ORIGINAL ARTICLE

Incapacity to give informed consent owing to mental disorder

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What renders some mentally disordered patients incapable of informed consent to medical interventions? It is argued that a patient is incapable of giving informed consent owing to mental disorder, if a mental disorder prevents a patient from understanding what s/he consents to; if a mental disorder prevents a patient from choosing decisively; if a mental disorder prevents a patient from communicating his/her consent; or if a mental disorder prevents a patient from accepting the need for a medical intervention. This paper holds that a patient’s capacity to give informed consent should be assessed clinically by using these conditions necessary for informed consent, and should be assessed specifically for each intervention and specifically at the time when the consent has to be given. The paper considers patients’ incapacity to give informed consent to treatment, to give informed consent to be examined clinically, and to give informed consent to participate in research.

NECESSARY CONDITIONS FOR INFORMED CONSENT

Notwithstanding standard conditions such as information, trust, and lack of coercion, we shall confine the consideration of the conditions necessary for informed consent to those that typically cannot be met owing to mental disorder. Thus, they are presented not as sufficient conditions, but each of them being necessary. They are:

i) a mental disorder should not prevent a patient from understanding what s/he consents to;

ii) a mental disorder should not prevent a patient from choosing decisively for/against the intervention;

iii) a mental disorder should not prevent a patient from communicating his/her consent (presuming that at least reasonable steps have been taken to understand the patient’s communication if present at all), and

iv) a mental disorder should not prevent a patient from accepting the need for a medical intervention.

The inability of some mentally disordered patients to meet the first three conditions is commonly cited. For some disorders, these conditions are indeed appropriately identified as those which at times cannot be met owing to the mental disorder. Some mental disorders prevent patients from understanding the nature and purposes of a medical intervention, or prevent patients from choosing decisively, or prevent patients from communicating their consent. Examples are dementia and learning disability of sufficient severity. A manic episode or a major depressive episode, for example, may entail marked indifference, ambivalence, or indecisiveness, any of which may prevent a patient from choosing decisively. Psychotic illnesses may also cause patients significant difficulty in understanding the nature and purposes of a medical intervention, or in choosing, or communicating their consent, as found in—for example, hebephrenic schizophrenia with markedly disorganised thoughts.

The Mental Health Act Code of Practice, reflecting the law in England and Wales, emphasises a patient’s understanding of the information about the proposed treatment, potential risks and benefits of treatment, and the consequences of not taking the treatment. It also requires a patient to have the capacity to make a choice. The Law Commission, in its consultation paper on mental incapacity, and the British government also consider “incapacity” in terms of “understanding” and “communication”. They say a mentally disordered person should be considered unable to take a decision on medical treatment in question if s/he is “unable to understand or retain the information relevant to the decision, unable to make a decision based on that information, or unable to communicate a decision”. Medical defence societies and various papers also take a patient’s understanding of information about treatment as the main determinant of his/her capacity to give informed consent.
The main problem that renders some mentally disordered patients incapable of informed consent does not, however, involve these conditions. The problem is that mental disorder prevents some patients from accepting that they need a medical intervention. We see this particularly in patients suffering from psychotic illnesses such as schizophrenia. They may understand the treatment proposed but still decline or refuse it because, in their judgment, they are not ill or do not need treatment for their difficulties. For example, a patient suffering from psychotic illness may assert adamantly: “I understand that you think I am ill, I understand your proposed treatment and potential consequences of my taking or my not taking the treatment, but I am not ill”; or: “I know I am ill and the proposed treatment and purposes of the treatment, but I don’t need treatment for it, because my illness will disappear in the near future when I will be God”. Such impaired judgment in patients suffering from psychotic illnesses is inherent to their illness. We clinicians commonly refer to this kind of judgment about their state of health as a “lack of insight” into their condition.

That the patient’s acceptance of the need for a medical intervention should not be prevented by his/her mental disorder, is a condition necessary for informed consent. If any patient, even if not mentally disordered, were to agree to treatment when s/he did not accept that treatment was warranted or necessary, it would cast serious doubt, to say the least, on whether such a patient actually gave informed consent for this intervention. Of course, there may be many reasons, valid or invalid, for not accepting that treatment is required. Clinical practice has it that a patient’s lack of acceptance that treatment is necessary is dealt with by honouring the patient’s choice irrespective of the reasons given.2 Patient refusals are presumed to be valid exercises of autonomy. Congruently, the Law Commission has recommended a “presumption against lack of capacity” and that the resulting decision should not be regarded as invalid just because it “would not be made by a person with ordinary prudence”.4

However, in the case of a patient who cannot accept that an intervention is warranted or necessary, owing to a mental disorder, such a patient’s choice is not autonomous because it is determined by the mental disorder. This also means that even if such a patient were to agree to an intervention, it would be farfetched to attest that s/he actually gave informed consent.

That a patient should believe the information about a proposed intervention, as suggested in case law,2 23 is also not always the appropriate necessary condition to determine capacity to give informed consent. For example, a deluded patient may state: “I believe the information you have given me about the proposed treatment, I believe the treatment may be beneficial for some and even for me, but I shall not take it because it does not befit me, being royalty from outer space, to take the medicine from common humans”.26

Of course, mental disorder does not necessarily prevent a patient from accepting his/her illness and the need for a medical intervention. Many patients, including those suffering from psychotic illnesses, do accept their illness and the need for medical intervention. And, while some may not realise the full extent of their illness, they can none the less give informed consent.

The clinician may find it helpful to have the above list of four necessary conditions at hand when questions arise about a patient’s capacity to give consent. It may be helpful in decisions about specific treatments. For example, say consent is sought to proceed with electro-convulsive treatment (ECT) for a severely depressed patient who suffers from the Cotard's delusion that he is dead already and who therefore considers treatment to be futile. Say the patient understands what he consents to—that is ECT, he communicates his decision to go ahead with the ECT, and he has chosen to follow the recommended advice. He thus meets the first three conditions necessary for informed consent. He will still not be capable of giving informed consent to the ECT, however, because his mental illness prevents him from accepting that he requires treatment.

The list of four necessary conditions may also be helpful in decisions about a patient’s capacity to consent to participation in research. For example, a patient who does not accept, owing to his/her mental disorder, that s/he requires treatment is also incapable of consenting to participation in research on medication for his/her illness. This is the case even though s/he understands the nature and potential consequences of the research, s/he chooses to participate, and communicates his/her willingness to participate. The reason is that his/her mental illness causes him/her to refuse the need for efficacious (non-placebo) treatment. S/he might even think that his/her participating in the research serves to prove that treatment is not really necessary. An argument against this stance might claim that it is not necessary that this patient accept the need for treatment, because a healthy person may consent to the use of research medication even though s/he does not need it. In fact, it is common practice to use healthy volunteers as controls in medication research. The difference, however, is that a healthy volunteer’s acceptance of not requiring the treatment, is not affected by mental illness.

The capacity of a mentally ill patient to give informed consent for a mental and physical clinical examination is a difficult issue practically, rarely addressed in the literature. The problem is that it is hardly possible for a clinician to assess a mentally ill patient’s capacity to give informed consent for a clinical examination until s/he has examined the mental state of the patient. Practically, this dilemma is posed in most civilised countries by provisions of law—for example, a mental health act, which may order or require a doctor to examine a patient even without a patient’s consent. When informed consent for a mental and physical examination is required, though, the same conditions are necessary as for informed consent to treatment and participation in research. A mental disorder should not prevent a patient from understanding the nature and purpose of the examination, from choosing decisively whether to have it done or not to have it done, from communicating his/her consent, and from accepting that the examination is needed or warranted.

THE EXTENT OF INCAPACITY TO GIVE INFORMED CONSENT

The Law Commission recommended, and the British government accepted, a “functional approach” in determining whether a person has the capacity to make a particular decision.4 This approach focuses on whether the individual is able to make a decision at the time when it has to be made. It allows for an individual to be incapable of making a particular decision at one point in time, but indeed capable to make it at another time—for example, after recovery. It also allows for situations where the individual is capable of making some decisions, but incapable of making others.

The conditions necessary to give informed consent, as they have been identified above, are concordant with this “functional approach” to making decisions. Capacity to make decisions is not to be confused, however, with the capacity to give informed consent. Capacity to make decisions is required for someone to give informed consent, but informed consent requires more than capacity to make decisions. It requires—for example, trust and lack of coercion.2 7 Moreover, informed consent requires more than mere capacity. As seen above, it requires that a mental disorder does not prevent “actual” understanding of what is being consented to (rather than a mere capacity to understand).

Furthermore, incapacity to give informed consent extends to incapacity to give informed consent to medical interventions as well as physical conditions. For example, say a patient were to agree to a medical intervention for his gangrenous leg, but his mental disorder prevented him from
understanding the nature and purpose of the intervention, or prevented him from communicating his consent despite all possible steps to understand him, or prevented him from choosing decisively whether to have it done owing to severe ambivalence, or prevented him from accepting the need for the intervention. Then, it would plainly be mistaken to claim that this patient’s assent to the intervention would constitute informed consent, for he fails, owing to mental disorder, to meet the conditions necessary for informed consent.

The same would apply in the following vignette. The patient suffered from paranoid schizophrenia with multiple delusions of persecutory, somatic, and grandiose types. He presented with a peritonitis that had ruptured into the abdominal cavity, a condition that required immediate life saving surgery. He understood the nature and the purpose of the proposed surgery, but he clearly communicated his choice not to have the surgery. On further inquiry, he revealed his delusions that he had magical spirits in his abdomen, which were the sources of his superhuman powers. He was certain that opening his abdomen by laparotomy would allow the magical spirits to escape, and without these sources of power he would die. He took it that the magical spirits would, in fact, heal the ruptured ulcer. Hence, his decision not to have had the surgery. Clearly, this patient’s mental illness prevented his acceptance of the need for surgery. He could not give informed consent for the procedure. Even if he had chosen to have the surgery despite having these delusions, thus believing his cure would come from the magical spirits rather than surgery, he would still not be capable of giving informed consent. His illness would still prevent his acceptance of the real need for the surgery.

Similarly, say a patient were to agree to participate in research on the treatment of an acute myocardial infarction, but his/her mental disorder prevented him/her from understanding the nature and purpose of the research, or from communicating his/her consent to participate in the research, or from choosing to participate in the research, or prevented him/her from accepting that s/he did not have to participate in the research. Certainly, such a patient’s assent would not constitute informed consent.

Incapacity to give informed consent to be examined is also not confined to examinations for mental disorders. For example, when a patient who suffers from advanced dementia does not understand the nature and purpose of, say, a genital examination, he/she cannot give informed consent for this (physical) examination. A patient’s incapacity to give informed consent to one intervention should not be assumed to imply incapacity to give consent to all medical interventions. It is well established in ethics and law that a patient may be incapable of giving consent to one intervention but capable of giving consent to another. For example, a patient suffering from schizophrenia may be capable of giving informed consent to the treatment of his/her diabetes but not to the treatment for his/her schizophrenia (or vice versa). Simply, a patient may meet the conditions necessary to give informed consent to the one intervention but not to the other. Thus, each proposed intervention would require an assessment of the particular patient’s capacity to give informed consent for that specific intervention.

The same is true of capacity in other respects, and particularly regarding performing actions. For example, a patient may be incapable of giving informed consent owing to his/her mental disorder, yet be capable of another action, say, making a cup of tea. By acknowledging that incapacity to give informed consent does not necessarily imply incapacity to perform other actions, however, another clinical and ethical problem is laid bare: even if a patient is incapable of giving informed consent owing to a mental disorder, the question remains whether this patient is also incapable of the actions of declining or even refusing a medical intervention. For practical purposes, the case may usually be that if a patient is incapable of giving informed consent, this patient would also be incapable of declining or refusing intervention. Nonetheless, the conditions necessary for someone to be capable of declining or refusing a medical intervention are not quite the same as the conditions necessary for giving informed consent. Consider the role of understanding: one might be capable of refusing an intervention without understanding the intervention. For example, one could refuse the hawker who approaches you even before you know what he actually wants (to sell). It could therefore be worthwhile teasing out, similarly to the present paper, the conditions necessary to decline or refuse a medical intervention, especially those conditions that cannot be met owing to a mental disorder.

In conclusion, the clinical assessment of a particular patient’s capacity to give informed consent in a case of mental disorder is best informed by the consideration of conditions necessary to give informed consent than by making inferences from the general features implied by a specific diagnosis. An assessment of a particular patient’s capacity to give informed consent by the consideration of conditions necessary to give informed consent may remain difficult clinically, yet such an assessment may strengthen ethically a clinical decision about a mentally disordered patient’s capacity to give informed consent.

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