

Assessing Decision-making Capacity in Dementia Patients: A Semi-structured Approach

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Abstract

One of the consequences of the rapidly increasing numbers of dementia patients in Singapore will be the need for all clinicians (including non-psychiatrists) to be familiar with the fundamentals of how decision-making capacity should be assessed. The clinical settings when the need for such evaluations arise, often involve cognitively or emotionally impaired patients who are required to make treatment, placement, financial or testamentary decisions. The clinician must first diagnose the patient's psychopathology and then go onto testing the functional abilities involved in decision-making. These comprise (1) making and expressing a choice, (2) understanding the relevant information, (3) appreciating the relevance of the information to oneself and (4) reasoning with the given information. The eventual judgement of the patient's decision-making capacity involves the weighing of impairment noted in any of the four decisional abilities against the potential adverse consequences of abiding by the patient's decision. The ethical impulse underlying this manner of judgement balances the respecting of patient's autonomy with protecting the patient from harm. Given the relative complexity of the assessment process, there is merit in developing a semi-structured approach to the evaluation of patients' decision-making capabilities; such an approach can guide a wider group of clinicians and psychologists through the essential steps of the process and thus enable the assessment to be more thorough, as well as fairer, to the patient.

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Introduction

Given the rapid ageing of Singapore, all practising clinicians can expect to see an exponential rise in the medical and surgical problems of the elderly. One such condition is dementia. Epidemiological studies by Kua et al^{1,2} have estimated local prevalence of significant dementia to be between 2% and 4% amongst those 65 years of age and above while more recently, Lim et al³ have shown the prevalence of cognitive impairment (including early stages of dementia) amongst Singapore's elderly Chinese to be much higher: 13.2% (95% CI: 9.4% to 17.7%).

The dementia syndrome typically presents with multifaceted problems in both patients and caregivers requiring a wide range of services and resources. Assessing the decision-making capacity of patients with dementia is one such problem. While ageing per se (without disease) has been associated with executive dysfunctions in

cognition,⁴ the prevalence of impaired decision-making increases considerably with a wide variety of neurological disorders commonly seen in the elderly, in particular, dementia. When these demographic trends are coupled with the growing awareness, from both the medical community and the public, of the need for informed consent prior to many types of medical interventions,⁵ clinicians can expect that very soon the need for assessing patients' decisional competence - a vital component of informed consent⁶ - will escalate significantly.

Assessing decision-making capacity often involves doctors (and this group includes non-psychiatrists) as well as psychologists. Given the anticipated rise in the volume of such cases in the near future, clinicians may however have to assess many cases on their own. Moreover, in certain common settings, such as evaluating patients' decisional abilities for choosing treatment or placement

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options, the patients' primary doctors will already be playing a fundamental role in the assessment process by conveying information about the illness and the risks/benefits of interventions to the patients. For these reasons, it becomes increasingly important for more doctors to know what decisional evaluation entails and like others,⁷ we believe that a standardised approach to decision-making capacity assessment offers many advantages to clinicians and psychologists. It guides the steps to be taken during the evaluation, ensuring that nothing important have been left out. Additionally, it allows the clinicians to better appreciate the rationale of the assessment process. All these can result in better quality of medical reports to lawyers, enabling the subsequent legal process for determining patients' competence to move more effectively and quickly.

In this paper we report on the elements of the semi-structured approach to assessing decisional capacity which we have found useful in our clinical practice. To complete the topic we also briefly touch upon the principles the clinician needs to keep in mind as she moves from the assessment findings to judging the patient's decision-making status. However, because of space constraints, the related subject matter of who should be, and in what circumstances, the alternate decision-maker as well as the principles of surrogate decision-making will not be covered herein.

Our approach, which is clinical interview-based, differs from other structured approaches reported in the medical literature. Thus, Marson et al favour the use of clinical vignettes (with standardised questions and scores) for such evaluations,⁸ but we have reservations of this indirect approach in terms of its final relevance to the patient's actual decision-making problems. On the other hand, while Grisso et al's structured method⁹ is also interview-based, the patient's responses to the stipulated questions are quantified and decisional capacity measured as a total score, requiring thus validation of the entire instrument to relevant populations and interpreting the scores statistically, against normative values. As will be seen, the approach we have taken is more qualitative and ordinal and while we acknowledge that the final conclusions require a careful exercise of judgement based on the findings of the assessment (as opposed to a statistical interpretation of scores), we believe our overall process to be more intuitive and realistic. (One way or the other, the need to exercise judgement is unavoidable, as exemplified by the fact that both Marson et al and Grisso et al point out that their structured approaches will still need to be combined with a separate clinical judgement of the patient's decision-making capacity.)^{5,10}

Assessment of Capacity: Overview

Decision-making capacity is the clinical equivalent of

competence, which is ultimately, a legal judgement. This distinction, however, gets to be blurred in practice, especially when doctors are called upon to make conclusions about cognitively-impaired patients' decision-making status in situations where these patients need relatively urgent treatment.¹¹ The ethical underpinning of decision-making capacity assessment is that if competence is demonstrated, then that person's decision, no matter how "irrational" (but not illegal), must be respected. Only when incompetence is likely to lead to adverse consequences, is society prepared to legally take away such a patient's decision-making rights and pass them to a surrogate. The patient's autonomy is balanced against beneficence to the patient (in terms of protecting the patient).

It can be useful to first ask what sort of tasks or settings prompt queries about patients' decision-making capacities. From our experience, the main ones are matters related to treatment, financial management, placement (institutionalisation) and testamentary capacity. Often, in these settings, the patients have already made unusual or questionable decisions (from the perspective of their clinicians or caregivers) or the doctors/relatives have sufficient concern about the patient's cognitive or emotional abilities to make correct decisions.

Following an appreciation of the setting, it will be important to know what the local legal requirements for competence assessment are. Section 9 of the Mental Disorders and Treatment Act (MDTA) states that if the court finds a person who is alleged to be mentally disordered to be "of unsound mind and incapable of managing himself and his affairs", the court may appoint a committee or committees of the person and estate. It then goes on to say that if the court finds that the person is "incapable of managing his affairs, but is not dangerous to himself or to others", the court may appoint a committee of his estate without appointing a committee of his person.¹²

The MDTA section just quoted first allows the clinician to realise that the legal end-points of any decision-making capacity assessment that shows impairment are essentially two: the appointment of a committee of person and/or the appointment of a committee of estate. Secondly, it makes clear that the courts will be looking out for certain *adverse consequences* arising from the patient's incapacity before the appointment of these committees, namely, the inability to manage his affairs (for committee of estate) and being a danger to himself or others (for committee of persons). In practice, "ability to manage affairs" is generally interpreted as an ability to manage finances, while being "dangerous to himself or to others" requires evidence that the patient is unable to look after his own safety or clear evidence that his acts are consistently endangering others (in a real or potential sense).

From this perspective, it can also be noted that of the four decisional tasks or settings mentioned above, treatment and placement-related tasks revolve around potential consequences to the patient that are, in spirit, the concerns of the committee of persons. Likewise, financial management and testamentary capacity settings raise potential consequences that may necessitate a committee of estate. It is important for clinicians to realise that the subsequent clinical interview, which essentially looks at how a patient is making decisions, is *always in relation to* these adverse consequences. This will be discussed further below in the section on the principles of judging competence.

Assessment of Capacity: Process

Preliminary Steps (Appendix I and II, Part 1)

The appendices show the semi-structured protocols that we use for decision-making scenarios involving treatment and placement. All such formats have two parts with the actual testing of functional abilities related to decision-making constituting the second part. The first section draws attention to the preliminaries that should be established before the testing process. Apart from stating the psychopathology, we believe it is useful to review the purpose and context of the assessment. For one, this determines the type of questions that the clinician will have to ask during the evaluation and for another, it allows the doctor to better appreciate the type of adverse consequences likely to be facing the patient should his decision be adhered to. In this regard, it will be appropriate also for the assessor to find out where possible, from the patient or significant-others, his relevant past values and beliefs which may explain the decision he is making.

Other important preliminaries, in selected settings, include relevant reports from medical social workers (who would have to investigate and report the patient's assets, if the scenario is one of ability to manage finances) or from occupational therapists (who may have to report, after a home visit with the patient, the patient's capacity for independent living, if the scenario is one of placement). The first section should also remind clinicians and psychologists undertaking the evaluation that the patient must be given sufficient explanation of the need for, and objectives of, the evaluation and that the patient has had opportunities to discuss pertinent matters with family members, close friends or doctors.

Psychopathology

Establishing a clear medical or psychiatric diagnosis that is causing the patient to be cognitively or emotionally impaired – his psychopathology – is a crucial first step and this is solely the clinician's responsibility. Where applicable, the attendant mental status or psychometric deficits should

be documented as there are now several studies showing the cognitive predictors of impaired decisional abilities in patients with neurodegenerative diseases.¹³⁻¹⁵ Likewise, the medical literature has highlighted how emotional distress can alone, without cognitive deficits, render decision-making capacity suboptimal¹⁶ and the affective status should also be specifically recorded. Without knowledge of the underlying psychopathology, it is difficult to know the *significance* or meaning, of whatever impairments one may be subsequently observing in the patient's functional abilities in decision-making.

The underlying illness can be acute or chronic, treatable or non-treatable and these aspects must be recorded as well as reflected upon. In those situations where the mental or emotional impairment is potentially reversible, the clinician may want to consider whether circumstances permit the assessment to be postponed till the patient has been optimally treated or supported (both physically and emotionally) – and sometimes, there may not then be a need for assessment.

Overview of Decision-Making Abilities

An impaired cognitive or emotional state is a necessary, but not sufficient condition for legal incompetence which also requires that certain task-related functional deficits exist¹⁷ (and, to reiterate, that these deficits are associated with an inability to manage one's affairs or that they can lead to harm to oneself or others). Thus, after a clinician has established the patient's psychopathology, the assessment next involves testing the functional abilities related to decision-making (and this can be done by a clinician or psychologist). This section touches upon some of the broader perspectives regarding decisional abilities, while the next focuses on the actual testing of these abilities.

Four functional abilities related to decision-making are well recognised in the medical literature and covered in this paper: making a choice, understanding disclosed information, appreciating the relevance of the disclosed information to oneself and lastly, reasoning with information to rationally explain the decision or choice. These abilities are also referred to as legal standards for competence. Understanding of disclosed information appears to be the most common legal standard adopted by the courts in the United Kingdom and the United States^{18,19} and several studies have also shown this to be the most stringent of all the four decision-making abilities among patients with Alzheimer's disease.⁸ There is both widespread legal concurrence as well as empirical evidence that making and expressing a choice is the most basic of all the legal standards (meaning if the patient fails on this standard, it is almost unnecessary to test other standards).²⁰

Research has demonstrated that the legal standards are not sufficiently correlated with each other²¹ and it is likely

that different diseases may present with different hierarchies of impairment among the four decisional abilities.²² These standards vary across courts in different jurisdictions, with some courts requiring only one and others requiring several, or even all four of the decisional abilities to be evaluated before deciding upon the patient's competence. As some have pointed out, judicial standards are very fact-sensitive, tailored to the specificities of each case and as long as the courts within a jurisdiction have not rejected the relevance of one of these four abilities, the possibility that they will adopt that standard in a future case which raises that need is very real indeed.²³ For these reasons, the pragmatic position we have adopted in this paper is that the assessment should cover all four abilities as far as possible. We believe that this approach has the additional virtues of rendering the evaluation more thorough and being fairer to the patient.

Testing Decision-Making Abilities

While the same four abilities are tested in each case of decision-making assessment, the exact form of questions to ask in relation to the abilities will differ from setting to setting, in accordance with the task at hand (Appendix I and II, Part 2). For treatment-related or placement-related scenarios, the assessor should ensure that, before testing the abilities, the patient has been given, in simple and clear terms, all the necessary and relevant information regarding the intervention. Steps must also be taken to correct, or sensibly minimise, any significant communication hindrances (including language/dialect difficulties and hearing impairment). As mentioned above, the patient should be informed of the purpose of assessment and be sufficiently stable emotionally to participate in the evaluation process.

Making a choice What is being tested here is the patient's *independent* ability to *make* a choice or decision (based on the relevant facts already given to him/her). Cognitive deficits such as receptive aphasia and severe dysnomia can inhibit this ability.¹³ That decision or choice should also be *consistent* and this can be assessed by asking the patient his choice a second time, towards the end of the assessment (or, in some instances, at a separate assessment). Needless to say, testing this ability also means that the patient is capable of *expressing* that choice or decision (which need not always be verbal). This test is generally regarded as being set at a very low level for competency and is thus the most respectful of patient autonomy.²⁴

Understanding disclosed information This tests the patient's ability to comprehend the relevant facts of the intervention or action that the patient is being asked to consider. Sufficient information should first be relayed to the patient with careful attention being paid to the above-

mentioned aspects of the communication process. Thus, in treatment-related scenarios, the patient should be told of the nature of his illness and of the suggested intervention, its risks and benefits as well as the risks and benefits of alternative treatments (including the option of no treatment). The patient should then explain in his own words what he has understood of that information. As a test for competence, understanding is considered to be set at a high level for competence.²³ Studies have shown that this decisional ability is impaired early in Alzheimer's disease due to deficits in conceptualisation, semantic memory and verbal recall.¹³

Appreciating information relevance Even when the patient has understood the relevant facts provided by the clinician, there may still be an inability to realistically apply those facts to one's own situation as a result of cognitive deficits (executive dysfunction)¹³ or, more importantly, impaired psychological states (via denial, distortions or delusions).²⁰ The patient may thus insist that the diagnosis of his condition is not true for him. For this to be established as a decisional disability, it is important that the clinician note that the beliefs are substantially distorted or irrational, they are relevant to the decision-making task at hand (in other words, the false beliefs are directly influencing the patient's choice) and above all, these distortions and denials are the consequence of an impaired cognition or affect.²⁰ The last feature must always be looked out for so as to prevent the assessor's biases against the patient's unconventional or even religious beliefs from insidiously creeping in; needless to say, this also means that the clinician must make reasonable efforts to know the patient's relevant past values. Appreciation is considered to be a moderately stringent test for competence¹³ and what is being evaluated is how the patient acknowledges his illness, its effects as well as the consequences of the various options to himself.

Reasoning with information This tests whether the patient is able to explain the decision or choice that incorporates the relevant disclosed information with his preferences in a coherent and consistent manner – whether the conclusions correspond with the starting premises and values. Cognitive deficits in attention and executive functioning have been shown to be associated with impaired decisional reasoning in patients with Alzheimer's disease.¹⁴ The assessor must be aware that judging the quality of the patient's reasonableness is again liable to be influenced by the assessor's biases and as a possible counter, it will be important to look at how the patient is weighing the risks and benefits of various options. For the same reason too, care must be taken to ensure that any perceived impairment in reasoning is arising from the patient's earlier established psychopathology. This test for competence is regarded as

a stringent legal standard¹³ and is best evaluated by asking the patient to explain how or why he made his decision.

Judgement of Capacity: Principles

Even after documenting the functional deficits observed during the decision-making capacity evaluation, there is still the challenge of knowing how to interpret the deficits in the context of the patient's specific circumstances. In some instances, when the patient fails all four abilities and is profoundly demented or retarded, the conclusion of impaired decision-making capacity is relatively easy to make. In other instances, the judgement is more complex and will be crucially bound to what the assessor selects as the functional ability or abilities (which are also termed as legal standards) that is deemed to be the most critical for the patient's decision-making status.²¹

Selection of the threshold functional ability or abilities for evaluating decisional capacity is partly influenced by the nature of the patient's underlying illness – thus, appreciation of information relevance (in terms of the values one attaches to the information in relation to oneself) can be significantly impaired in patients with depression, while their other decision-making abilities (making a choice, reasoning or understanding) remain intact.¹⁶ More critically though, the selection of the relevant legal standard is tied up with ascertaining the risk-benefit consequences of abiding by the patient's decision²⁴ (and, if it can be ascertained, an important factor for defining what are risks and what are benefits is the patient's relevant past values and beliefs).

In situations where the patient's choice will be resulting in a potentially high risk-poor benefit outcome, the patient will be expected to pass more stringent legal standards such as a clear understanding of the relevant issues. Conversely, if the patient's decision is likely to be ending up in a low risk-good benefit outcome, the patient need only evince a low threshold of decision-making ability (such as the ability to consistently express a choice). The underlying ethical principle is not to remove, as far as possible, the patient's autonomy to make his own decision – unless that decision is likely to be leading to a clear harm. In that spirit too, for all other situations where the outcome is likely to be moderate risk-moderate benefit, the general preference often is to abide by the patient's decision.²³

Whatever the final judgement about the patient's decision-making status, it will also be useful to reflect upon the time-dependent dimension of the conclusion. Thus, if the patient is deemed competent, that assessment obviously does not preclude a future decline and conversely, if incompetence is ascertained, the question of whether it is potentially reversible should also be given thought. In some instances, these considerations may indicate the need for reassessment at a later point in time.

Judgement of Capacity: Documentation

Given the medico-legal climate directly surrounding decision-making capacity assessments, it is essential that clinicians carefully document the important steps taken, the attendant findings, the final conclusions and the underlying rationale for those conclusions. It may be necessary at a much later point in time to review the whole assessment and good documentation then plays a vital role in reminding one to know how the earlier decision was arrived at.

It is also for the above reason that we believe the semi-structured clinical interview method of decision-making capacity assessment to be advantageous. It ensures that the clinician has gone through the necessary preliminaries and it guides the actual evaluation during the clinical interview. The findings are documented into the form and the final conclusions and rationale can be recorded in the case-sheets. The subsequent medical report to the lawyer thus becomes easier to write. In submitting this report, there may also be a need to append related assessment reports (such as those from psychologists, occupational therapists or medical social workers).

Conclusion

One of the consequences of dementia is progressive loss of decision-making capacity and with the projected demographic escalation of this condition, more doctors will need to be conversant with how patients' decisional abilities (especially for treatment-related options) are to be assessed in the wards or clinics. From experience, we find the semi-structured, clinical interview approach to be useful. It makes the clinician's tasks for decision-making capacity assessment easier as well as sufficiently thorough. While guiding the essential steps of assessing the relevant functional abilities, it does not, however, remove the clinician's need to exercise judgement in ascertaining the patient's decision-making status. This paper has also discussed the principles to be observed in making that final judgement. Ultimately though, the courts reserve the final right to agree with, or reject, the physician's conclusions.

It also needs to be stated that in sharing the semi-structured format, we are not proclaiming that this is the way that all decision-making capacity must follow. We recognise that there is a diversity of approaches, many of which are adequate and valid. From the system point of view, however, we think a semi-structured approach to clinical evaluation has greater potential for ensuring a more widespread meeting of adequate standards, a consideration that is relevant when one anticipates the rising tide of such cases. We are aware too that future improvements will be necessary as more experience accrues and in sharing our present format, we hope that others will further build upon

these initial endeavours.

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APPENDIX I

COMPETENCE FOR DECISION MAKING: TREATMENT

A. REASONS FOR ASSESSMENT OF COMPETENCE

1. What psychopathology does the patient have? (e.g. dementia, significant mood disorder, psychotic illness).
-
-
- This must be ascertained by an appropriate specialist (please attach relevant documents).
2. Capacity for consent is queried because of:
-
-

3. Please determine, as far as possible, any of the patient's past values, preferences or beliefs relevant to the decision at hand and also ensure that patient has been given sufficient explanation, time and opportunities to discuss pertinent matters with family members and primary clinicians.

.....

.....

These must be satisfied before you proceed further.

B. ASSESSMENT FOR TREATMENT CONSENT

Making a Consistent Choice – Part 1

1. Make a treatment choice
- What is your treatment choice?*
-
-

Understanding and Appreciating the Matter at Hand

2. Know the nature of the proposed treatment
What illness are you having? What is the treatment advised by your doctors?
.....
.....
3. Know the possible benefits of the proposed treatment
What can the treatment do for you? How will the treatment help you?
.....
.....
4. Know that there are possible risks of the proposed treatment
Are there any risks from the treatment? If yes, what are the risks?
.....
.....
5. Know the nature and consequences of no/alternative treatment
If you do not want treatment, then what would you like? What is your preference?
.....
.....
6. Know the possible benefits of no/alternative treatment
What are the benefits of your preference?
.....
.....
7. Know the possible risks of no/alternative treatment
What are the risks of the preference?
.....
.....

Making a Consistent Choice – Part 2

8. Make a consistent treatment choice
Can you tell me again your treatment choice?
.....
.....

Ability to Offer a Reasonable Explanation

9. Able to explain his/her decision (assuming patient is not undecided and has had sufficient time)
Can you explain why you have made this choice?
.....
.....

APPENDIX II

COMPETENCE FOR DECISION MAKING: PLACEMENT

A. REASONS FOR ASSESSMENT OF COMPETENCE

1. What psychopathology does the patient have? (e.g. dementia, significant mood disorder, psychotic illness).
.....
.....
This must be ascertained by an appropriate specialist (please attach relevant documents).
2. Capacity for consent is queried because of:
.....
.....

3. MSW has already determined patient's placement options.

Please attach relevant documents.

4. Occupational Therapist has already determined patient's risk of community (solitary) living.

Please attach relevant documents.

5. Please determine, as far as possible, any of the patient's past values, preferences or beliefs relevant to the decision at hand and also ensure that patient has been given sufficient explanation, time and opportunities to discuss pertinent matters with family members and primary clinicians.

.....
.....

These must be satisfied before you proceed further.

B. ASSESSMENT FOR PLACEMENT CONSENT

Making a Consistent Choice – Part 1

1. Make a choice
Can you tell me where you would like to go after the stay in hospital?
.....
.....

Understanding and Appreciating the Matter at Hand

2. Know his/her medical condition and functional status (understands medical problems, physical abilities/disabilities).
Do you have any difficulties in looking after yourself, either at home or outside the home?
.....
.....
3. Understand his/her social situation (ability to look after self with/without supervision; lack of carers; financial situation; insight into social support system).
Who is looking after you? Do you think you need others to help you out, for example, on dressing, bathing, taking medication etc? How can you financially support yourself?
.....
.....
4. Know the consequences of each placement option (able to acknowledge the advantages and disadvantages of staying alone at home/Nursing Home/other places)
What are the advantages and difficulties of staying in your own home, or in a Nursing Home/other places?
.....
.....

Making a Consistent Choice – Part 2

5. Make a choice on where he/she would like to go (assuming that patient is not undecided and has had sufficient time).
Can you tell me again where you would like to go after the stay in hospital?
.....
.....

Ability to Offer a Reasonable Explanation

6. Able to explain his/her decision
Can you explain why you have made this choice?
.....
.....