Assessing Mental Capacity

Complex decision making involves multiple cognitive domains. It is not surprising that correlating specific cognitive domains with capacity is challenging. Even when capacity is broken down into the basic components of understanding, weighing up choices, recalling information and expression of a choice, correlations with specific cognitive domains are variable, and of moderate strength. Similarly, correlations between capacity and global cognitive functioning are mixed. A score of 19 or less on the Mini-mental state examination (MMSE) robustly predicts incapacity, but a higher score does not guarantee capacity [21].

There is considerable heterogeneity within patient groups. Individuals scoring highly on neuropsychological tests may lack capacity, whilst others with significant cognitive impairments retain it [22]. One risk that may undermine the scope of capacity assessments is that they become a memory test—some involve extensive questioning, which draws heavily upon memory. Further work in people with neurodegeneration would be of great interest, particularly investigating the role amnesia plays in impaired capacity.

Overall, whilst global cognition correlates to some degree with capacity status, there are no definitive rules that can be applied. More complex decisions will require greater cognitive ability. Therefore, people with mild dementia may be able to make informed decisions about a simple, low risk, high benefit change to medication, but not about a complex surgical procedure with a borderline risk/benefit ratio.

Even mild cognitive impairment can considerably impact on decisional capacity [16, 21, 23]. Understanding, retaining and using information are typically impaired, with expression of choice often remaining intact [24]. It has been suggested that expression of choice is less cognitively demanding than other aspects of decision making [23]. As dementia progresses, there is a concomitant progressive loss of capacity. Clinicians should elicit opinions on future care at an early stage, to use in future ‘best interests’ decisions when an individual has lost capacity.

Cognitive fluctuation and capacity

Many conditions cause a fluctuating cognitive state, for example Lewy body disease and delirium. Capacity can vary day-to-day, or even hour-to-hour. Ways to optimise capacity include approaching an individual on a ‘good day’ (best identified by the patient, relatives or knowledgeable carers) and at a preferred time of day (e.g. avoiding the evening, when confusion may worsen).

Traditionally, decisions regarding competency ultimately rest with the assessor, but how well different professionals agree with each other and structured assessments is unclear. Informal ratings by the professionals or relatives are much less reliable than either expert opinion or structured assessments This may reflect the information available—if understanding, recall and decision making are not specifically probed then clear-cut impairments may be missed. Health and social workers may assume capacity is present because either an individual agrees with the professional’s plan, or they say ‘yes’ when asked if they understand. Such superficial assessments are inadequate and will miss both those lacking capacity, and those who with support (e.g. simplified information) could achieve capacity.

Whilst many studies are limited by small sample sizes and limited replication, they highlight variability in clinician judgement, and bring into question what should be our gold standard capacity assessment. It has been suggested that in clinical practice, clinicians may equate treatment refusal with lack of capacity and treatment acceptance with competency. Thus, a capacity assessment may only occur if the patient refuses treatment. Whilst the UK legislation presumes capacity to exist until demonstrated otherwise, we must be careful not to abandon the patient to their rights. Health and social care professionals must be vigilant to prevent neglect, particularly when individuals with complex neurodegenerative or neuropsychiatric conditions refuse interventions. There is a risk of serious harm to those who refuse medical or social care, and professionals who fail to conduct adequate and timely capacity assessments may be guilty of wilful neglect.

Assessing capacity is clearly more challenging in borderline cases. In such cases using structured tools or seeking a second opinion from a trained professional is sensible. Disagreement about capacity (either between professionals, or between staff and the patient or relatives) should prompt a detailed assessment and open discussion. This will allow people to be supported to have the highest level of capacity possible and permit those lacking capacity to have their views heard.

Defining and judging mental capacity requires a fine balance between patient autonomy and protection of vulnerable adults. The UK legislation provides a clear framework for clinicians and researchers when assessing capacity. However, there are contrasting legal and clinical approaches: clinicians often view capacity as a gradient, whereas the legal approach is more dichotomous. With patient rights' reliant on judgements of decision-making capacity, it is imperative that such assessments are reliable and valid. The greatest challenge is the current lack of a gold standard. The complexity of capacity assessment means it is unlikely to be successfully reduced simply to a score on a memory test, or tick boxes in a questionnaire. Cognitive abilities, alongside patient emotions, values and experiences are all valid factors that contribute to decision making. No current instrument is sufficiently flexible or broad in scope to consider individual and contextual factors in the assessment of capacity and for this reason expert judgement and due attention to patient values and narratives are essential. There is a pressing need for more research in this area but also for more widespread and thorough training for clinicians and researchers. There may even be scope to develop more standardised and universally agreed approaches to the assessment of capacity. Whilst there is a high level of awareness of the UK capacity legislation amongst healthcare professionals and researchers, there is often a lack of understanding of the detailed components that make up capacity and hence more standardised approaches may be helpful. These must always be assessed in a sensitive and careful fashion, to both maximise a person's decision-making abilities and to protect those persons who are unable to make decisions for themselves.

Tools for testing decision-making capacity in dementia

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