

WHY WE SHOULD ASSESS DECISION-MAKING CAPACITY (EVEN THOUGH WE CANNOT)

Almost a year ago, I nervously parked outside a large stone house in north Derbyshire on a frosty winter morning. I was here to see Henry, an 80 year old retired optician who had been diagnosed with Alzheimer's disease four years previously. Henry's wife, Julie, welcomed me at the door before leading me into a conservatory to meet her husband. Henry greeted me warmly from his wicker chair and we discussed the peak district for a while. Though he repeated himself a few times, it wasn't immediately evident that he had any significant cognitive impairment, and we had an enjoyable conversation. Little indicated the gravity of the judgement that I was soon to cast over Henry. After a short while, we moved and sat down at a table by the conservatory windows to begin an assessment.

The assessment was to ascertain whether Henry had legal decision-making capacity. The decision in question was whether or not he should participate in a research project - my own research project - exploring informal dementia care. During the year since this assessment, I have often contemplated Henry's case, alongside subsequent assessments conducted with other people with dementia, with a degree of uneasiness. This essay indulges my uneasiness, first asking the question: can we assess decision-making capacity? Bluntly, I consider the answer to this question to be 'no'. Capacity assessment relies on ill-defined concepts and is largely reliant on assessor subjectivity. In response, I feel a need to recast the question, asking: should we assess decision-making capacity? To this question, my answer differs. Capacity assessment does provide a rough guide, which is preferable to unmitigated decision-making. Though we cannot assess capacity, we do need to try. Our current system of crude assessment, though flawed, remains the best available option.

Mental Capacity Legislation

The key piece of legislation regarding decision-making capacity in England and Wales is the Mental Capacity Act 2005 (MCA)¹. The MCA is applicable to people aged above 16 in England and Wales who have an impairment of, or disturbance in, the functioning of the mind or brain. This applies to all those diagnosed with cognitive impairments of any kind, dementias being a good example. Two categories of person are delineated, those who have the capacity to make decisions, and those who do not. Creating this distinction generates a need for capacity assessment, and therefore for a capacity assessor to conduct that assessment. These

¹ MCA 2005

requirements are based on the assumption that we are able to assess mental capacity as being sufficient or insufficient to enable decision-making.

As an example of the process, the assessment of a person's capacity to consent to participate in research begins with presenting the potential participant with information about the decision to be made. This is usually in the form of an information sheet, outlining relevant study details. The assessor should ensure that all reasonable efforts to enhance the person's understanding of this information are made. For example, people with cognitive impairment often function best during a specific time of day, so this is the best time to conduct an assessment. Once the person has received the information, they are ready for assessment. Assessments are usually conducted by a member of the research team. The assessor questions the person being assessed regarding the study and participation in an attempt to answer the following questions:

- Does the person understand the decision?
- Does the person understand the consequences of the decision?
- Can the person understand, retain, use and weigh up information?
- Can the person communicate their decision?

If the answer to all of these questions is yes, then the person has the capacity to make the decision. If the answer to any one question is no, then the person lacks capacity. Deciding whether or not a person has decision-making capacity should be based on this process alone. No person can be assumed to lack capacity before being assessed, even those who are seemingly catatonic. Cognitive battery scores cannot be used to judge capacity and a person cannot be deemed to lack capacity because the decision that they make appears to be unwise or incorrect to others. This is the basic legal position on capacity.

Capacity's Boundaries

The MCA's provisions are an attempt to solidify the concept of capacity, yet the difference between neat legislation and complex real-world practicalities can often be substantial. Therefore, to explore whether we can assess decision-making capacity, it is useful to consider Henry's case in greater detail. Henry was a particularly interesting case because he narrowly lacked capacity in an initial assessment, but narrowly had capacity at the second assessment. The MCA allows for a second assessment in borderline cases, and Henry was very much a borderline case. What does this borderline entail in practice? I began the assessment by presenting Henry with an information sheet. He read this and said that he understood and was happy to participate. I then asked him to tell me about the study, why he would like to take part and what he thought his participation would involve. My intention was to weigh his responses as evidence against the four aforementioned capacity criteria. Henry's first responses were generally appropriate but vague. He said that he wanted to help dementia research but did not appear to understand what participation entailed when pressed. I was therefore not comfortable

deeming him to have decision-making capacity. After a brief pause, we repeated the process. This time Henry did appear to understand that his participation would involve me asking him and his family questions about their lives and his condition. With this, I was satisfied that he had capacity.

Henry's case offers important lessons regarding capacity assessment because he occupies a conceptual frontier. When we construct a divide between capacity and incapacity, the progressive nature of the cognitive decline which characterises dementias means that a person will likely transition from one side to the other over time. People like Henry are doing just that, and in doing so straddle a conceptual boundary. Such people have an invaluable ability to make us reflect on our systems of classification.

The major source of my subsequent ruminations regarding Henry's case is the sense of subjectivity that I took away from the experience. Despite the MCA's attempts to rigidly define capacity criteria and the assessment process, the realities of capacity assessment remain nondescript and somewhat hazy. As I drove home following Henry's assessment, it occurred to me that, were ten people to assess him individually, it would be unlikely that Henry would be unanimously deemed capable or incapable of making a decision. The issue here is one of subjectivity. Capacity legislation aims to reduce subjectivity by stringently defining process, and to an extent this is successful. However, no matter the minutiae of the MCA or the lengthy expert deliberation underpinning it, subjectivity will remain. This is because the central concepts within this issue are indefinite. In practice, capacity is more art than science.

When first reading the aforementioned questions comprising the capacity assessment, you may notice that the word "understanding" appears in three of the four questions. To have the capacity to make a decision, a person must understand the decision, the consequences of the decision and the information provided. An immediately obvious problem with understanding is how to decide if somebody understands. To assess whether somebody understands the decision during a formal assessment, the assessor may ask them a question along the lines of, "What decision are you being asked to make?" If they answer, "Whether I wish to participate in this research", does that mean that they understand the decision, or are they simply parroting the information that the assessor recently conveyed? What warrants understanding? There are various legal², psychological³ and philosophical⁴ models of understanding. However, this essay is interested in practicalities, and the answer to this question in actual assessments is that understanding is whatever satisfies the assessor.

This issue feeds into another problem with our approach to assessing decision-making capacity: what degree of understanding is sufficient to warrant capacity? Evidently, it is possible to hold varying degrees of understanding. As a dementia researcher, I would hope that I have a better than average understanding of dementia. Still, I would hazard a guess that some

² Lipshaw 2008

³ Reed 2013

⁴ Grimm & Hannon 2014

people have a good deal more understanding of the subject than me. Despite this, the MCA's aforementioned criteria are notably vague when it comes to defining appropriate levels of understanding. Again, in practice the level of understanding that is sufficient to have decision-making capacity is that which satisfies the assessor during the assessment.

In the context of decision-making, the idea of understanding is further complicated. Capacity is only questioned regarding those with cognitive impairment, and this is purely because they have been deemed cognitively impaired. This may be unwarranted. Few people can be expected to fully understand the intricacies of the kinds of decisions that usually invoke capacity discussion. Consider the decision regarding a Do Not Resuscitate order. Is a palliative care nurse, recently diagnosed with dementia, automatically likely to be less capable of making such a decision than an estate agent with no cognitive impairment? Understanding is dependent on a broad range of factors, and is more intimately bound up with the individual than legal definitions of cognitive impairment account for.

Related to this issue is the additional consideration of context dependent capacity. Legislation can present the illusion of mental capacity as a simple equation. However, the capacity to make a decision is not solely dependent on the decision-maker's level of capacity being equal to or greater than the level of capacity required to make the decision. A person's decision-making capacity may vary depending on the way the decision is presented. For example, some financial decisions are couched in such convoluted jargon that I lack the capacity to make such decisions, or at least the context reduces my capacity in relation to the decision. Were the language simplified, I may well have a greater ability to 'understand' and 'weigh up' relevant information. This reveals that capacity is context dependent. Legislation acknowledges this when encouraging reasonable steps to facilitate capacity. As discussed, assessing capacity at the right time of day can make the difference between somebody having or lacking capacity. However, context can only be manipulated to an extent, meaning that assessment results will always be a partial function of factors beyond pure internal cognition. If somebody fails a capacity assessment, how can we know that it is not due to a combination of tiredness, medication, the assessor's accent and a visual distraction, each contributing to a reduction in the person's capacity to make a particular decision?

Legislation also recognises that context is not the only driver of fluctuating capacity. Decision-making capacity can fluctuate without apparent external cause. Such is the nature of cognitive impairment that a person may have substantially different cognitive abilities within the same hour. For example, delirium can often appear and dissipate remarkably quickly, suddenly rendering people extremely cognitively impaired, before returning them to lucidity. Just as Henry's case undermined my own faith in the reliability of capacity assessment, I have spoken with researchers who were unconvinced of their own assessments' reliabilities due to the intuition that participants were repeatedly moving in and out of having capacity during research. In such situations, the MCA stipulates that a new assessment should be conducted whenever an alteration in capacity is suspected. However, in practice it is unrealistic to conduct

capacity assessments on an hourly basis to reaffirm decision-making. Considering this fluctuation, even if a perfect measurement of capacity was available, it would not offer a practical grounding for legislating decision-making, as such decisions could be recurrently undermined and reaffirmed.

Subjectivity in Substantial Judgements

The aforementioned issues mean that the assessment of decision-making capacity is subjective to a considerable extent. The issue of subjectivity speaks to the question of whether we can assess decision-making capacity without prejudice. Prejudice is a strong word, but considering the degree to which the assessor's pre-conceived ideas influence the assessment, the answer is likely 'no'. To a certain degree, the assessment result is a function of the assessor, rather than dependent on the person being assessed. This is not to say that the assessor is making entirely baseless judgements. Legislation offers guidance regarding the parameters of assessment, but it cannot completely define the terms of capacity. Assessor interpretation is still required. Thus, what I have described so far can be broadly considered a two-stage inadequacy. First, the concepts employed within the notion of decision-making capacity undermine validity. Second, their execution through human assessors undermines reliability.

Of course, subjectivity in itself is no bad thing. What makes the subjectivity of decision-making capacity assessment problematic is the gravity of the judgement being made. Deciding that a person cannot legally make a personal decision is a definite act of disempowerment. A person is stripped of a significant legal right. That such assessments are subjective is troubling to anybody concerned for the welfare of people with cognitive impairment and the protection of their legal rights. Furthermore, not all decisions are equal. In Henry's case, we are talking about the decision to participate in interviews. Though negative ramifications are possible, the decision is unlikely to be particularly life-changing. In more serious cases, the decisions to be made may pertain to financial management and medical interventions. As a result, the subjectivity of capacity assessments becomes a grave concern.

Considering these recognitions, assessing capacity was one of the most uncomfortably direct experiences of power inequalities that I have ever encountered. As a stranger, I entered people's homes, and within a short space of time reached and enacted profound verdicts regarding those people's legal abilities to make decisions for themselves. Had our roles been reversed, I must admit that I would have been somewhat aggrieved. Awareness of the issues discussed so far only serves to make the job of assessing capacity more difficult. With so many problems negating our ability to assess decision-making capacity, it is only natural to wonder why we attempt to assess capacity and whether we ought to scrap assessment all together. In actuality, assessment is begrudgingly accepted as a necessary evil because there is no practical

alternative. I will now discuss the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁵ to reveal why this is.

Indiscriminate Idealism

The UNCRPD came into existence shortly after the MCA. Their approaches to decision-making capacity contravene each other⁶, despite England and Wales officially respecting both. As yet, no attempt has been made to rectify this tension and the MCA continues to operate as the accepted legal approach to capacity in England and Wales. The chief dispute between the UNCRPD and the MCA is the discrimination of legal rights based on cognition. Article 12 of the UNCRPD protects equal recognition before the law regardless of disability. The MCA's rationale is to discriminate between legal statuses based upon cognitive impairment. These two aims are seemingly at odds with one another. Given the inadequacies of attempting to distinguish those who have capacity from those you do not, might the UNCRPD offer a preferable model? The UNCRPD's outright rejection of capacity discrimination certainly deals with the aforementioned criticisms of assessment in one fell swoop. Uncertainties around the concepts of cognition, capacity and understanding are forfeit in a system under which they are inconsequential.

The simplicity of equal recognition before the law as an approach to decision-making capacity belies its impractical idealism. To highlight why this is, I want to discuss April's case. April was an 82 year old retired teacher diagnosed with Alzheimer's disease. I assessed April's capacity directly after Henry's. Unlike Henry, April was not a borderline case. She very evidently lacked the capacity to decide to consent to participation, having no recollection of the study almost immediately after discussing it⁷. While interviewing April some time later, she offered to drive me a considerable distance to her birthplace, despite having been banned from driving for some time due to safety concerns. Suppose that such prevention was illegal, and the only way that driving licences were forfeit was if their owners decided to return them. If April had had free reign over this decision, the repercussions would likely have been catastrophic.

Repeatedly in my work with people with dementia, the removal of driving licences against people's wills is articulated as one of the worst aspects of diagnosis. People are commonly angered to find that they are not able to make their own decisions as to when to retire from the roads. It causes notable harm to some, both emotionally and practically in terms of logistics and isolation. Yet few would reasonably argue that these people should be able to make this decision for themselves in such circumstances, given the possibly disastrous ramifications. It

⁵ UNCRPD 2006

⁶ Bartlett 2012

⁷ Admittedly, given the above discussion, who's to say that some assessors would not have deemed her capable?

is a stark example, but I have found that driving is a common source of contention and exemplifies the point that some decisions should not be made by the person without official consideration.

Considering the potential implications of the UNCRPD reveals its problematic simplicity. Its rejection of discriminatory capacity assessment is well-intentioned, but such idealism is ill-suited to the practical decision-making hazards of cognitive impairment. Sometimes discrimination is the lesser of two evils. This realisation grants us a renewed appreciation of the MCA and its provisions for the classification of those with and without decision-making capacity.

A Rough Guide

Despite the MCA's failings, the flaws in the UNCRPD's approach are important in highlighting the positive aspects of the MCA. Having criticised its central features and its approach to capacity assessment, I will now attempt to at least partially mount a defence of capacity assessment as a flawed but ultimately necessary tool. Put simply, assessment points in roughly the right direction and is therefore better than nothing.

The above criticisms of capacity assessment revolve around subjectivity, which in my experience is a major problem and should not be discounted. However, although capacity assessment is not an impeccably valid or reliable method of judging whether a person can make a decision, it is also not entirely random or meaningless. As mentioned, my research population of people with mild to moderate dementias sits astride a conceptual boundary, and in doing so emphasises certain theoretical difficulties in delineating capacity. However, for those with mild cognitive impairment⁸ or late-stage dementia, the assessment of capacity is much more straightforward. My concern that Henry would receive varied judgements from different assessors would be much less warranted were he to have mild cognitive impairment or late-stage dementia.

It should also be acknowledged that capacity legislation has improved the decision-making process for people with advanced dementias by providing an accepted legal process. Let us not forget that without assessment legislation, decision-making capacity is solely a matter of whether the powerful deem it to exist or not. Under this system, various parties, from judges through to a person's next-of-kin, could exercise relatively unconstrained power over the decisions of people with cognitive impairment without any imperative to respect their autonomy. Historically, carers have commonly been considered legitimate proxy decision-makers on behalf of people with cognitive impairments simply by virtue of those impairments. This is at least now illegal under the MCA, even if not always respected as such.

As for those cases that sit on the boundary of capacity and appear to undermine assessment, one must reinterpret the assertion that assessment is more of an art than a science in order to

⁸ Cognitive impairment not severe enough to be diagnosed as a dementia

adopt a more positive view. There is nothing wrong with art after all. Just because assessment does not precisely score capacity against a standardised measuring scale, this does not mean that it does not point in roughly the right direction. When the borderline cases are considered in conjunction with the clearer cases, it is likely that the vast majority of assessments provide a reasonable picture of whether or not the person has decision-making capacity.

Put simply, working to a rudimentary indication is better than doing nothing and allowing fate to take its course. Without assessment, decisions are either left to the person, irrespective of their capabilities, or appropriated by another more powerful individual. If decisions fall blindly to people who would otherwise be assessed, then it is likely that a proportion of those decisions will be made by people who lack capacity, with potentially avoidable dire consequences. If decisions are apprehended by other individuals, then it is equally likely that people who are able to make decisions for themselves will be prevented from doing so. Such decisions may be made in the interests of others, or in line with incorrect perceptions of the wishes of the person. Even crude capacity assessment is manipulating the odds a little in the interests of empowering and safeguarding people with cognitive impairments.

Conclusions: We Cannot . . . But We Must

To return to the initial question, can we assess decision-making capacity? The simple answer is ‘no’, or at least ‘not well’. In practice, ascertaining on which side of an indeterminate cognitive boundary a person falls at any given time is more art than science. This is troubling considering the severity of the judgement to be made. Through assessment, we can only construct vague impressions of a person’s cognitive abilities, and then weigh those abilities against our subjective understanding of what abilities are required to warrant decision-making capacity. However, this ‘no’ comes with a somewhat contradictory caveat. We cannot assess capacity, but sometimes we need to. While capacity assessments are crude and likely often easily contestable, in certain situations such as April’s, it would be imprudently idealistic to allow unchecked decision-making regardless of capacity.

Instead, we can consider the decision-making process for people with cognitive impairment to be an odds game. There are risks of both reckless personal decision-making and unnecessary proxy decision-making. In this context, capacity assessment offers a broad indication that allows us to tip the balance in favour of empowering people to make their own decisions, while safeguarding those who cannot make informed decisions and risk causing harm. The unavoidable downside of this is that some people’s autonomy becomes collateral damage, sacrificed in the pursuit of general safeguarding. Any system that is so rough around the edges will inevitably have regrettable results occasionally. My argument is that ‘occasionally’ beats ‘frequently’.

In truth, the answer to this question could easily have been a straightforward ‘no’. I have detoured considerably because it is important to qualify this answer to give a more balanced

view of capacity assessment in practice. The fact that we cannot do something does not necessarily mean that we should not try. This is something that is often overlooked in on-going debates around our capacity legislation. The issue can easily become so idealised as to produce irreconcilable positions. Ultimately, such debate translates into a lack of practical solutions for addressing important issues. There is little that is ideal about cognitive impairment, so there is little reason to expect our responses to be ideal.

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