Mental Capacity Act (2005) assessments: Why everyone needs to know about the frontal lobe paradox

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Patients with frontal lobe damage can perform well in interview and test settings, despite marked impairments in everyday life. This is known as the ‘frontal lobe paradox’. Failing to take account of this when conducting Mental Capacity Act assessments can result in disastrous consequences for patients. We suggest that neuropsychologists work collaboratively with local authority social workers and care managers, who often have the final say in such assessments, to raise awareness of this issue.

Introduction

There is a subset of patients with prefrontal cortex (PFC) damage who appear proficient within clinical interviews and perform normally on traditional office-based assessments. At the same time, however, they exhibit marked limitations within the domain of adaptive functioning. This is referred to as the ‘frontal lobe paradox’ (Walsh, 1985) or the ‘knowing doing dissociation’ (Teuber, 1964).

Although the frontal lobe paradox will be familiar to many neuropsychologists, this enigmatic form of vulnerability can be overlooked by other professional groups. When this results in a patient being misclassified as having mental capacity, it can prevent them from receiving the care or supervision that they require. In some cases, it can leave them at risk. Of course, this is quite distinct from the situation whereby a capacitious patient chooses to make an unwise decision. The aim of this paper is to raise awareness of this issue and to trigger a debate about the way forward.

The problem with interview-based assessments

Mental Capacity Act (MCA) assessments take the form of interviews which focus upon the patient’s ‘decision making capacity’ (Owen et al., 2017, p.134). The problem with this approach is that the difficulties experienced by people with PFC damage manifest themselves more clearly outside of an interview setting. One reason for this is that decrements in executive and adaptive functioning are often masked by preserved language (McCrea & Sharma, 2008) and verbal reasoning skills, so much so that an individual may appear remarkably unimpaired.

Another problem is posed by the fact that a hallmark of the frontal lobe paradox is a lack of insight. Patients with PFC damage may grossly overestimate their adaptive skills and consequently, underestimate their need for support or supervision. Williams and Wood (2017) highlight that these individuals are typically ‘able to describe what they should be doing in logical terms when asked in the abstract, but in practice, fail to use this knowledge to guide their actions’ (p.37). Put another way, they are good in theory but poor in practice.

Functional impairments may also be hidden from view within a rehabilitation or ward environment. The structure and routine within these settings, coupled with the high level of implicit and explicit support, means that there may be few opportunities for executive deficits to come to light. Clearly, it is difficult to detect if people are failing to adapt
their behaviour in accordance with post-injury limitations (Priestly & Manchester, 2014) when few cognitive demands are being placed upon them. The ‘absence of skilled observers’ (Worthington, 2012, p.370) is a further issue.

The problem with diagnosis

It has long been recognised that a number of people with frontal lobe damage have clear impairments in everyday life but little or no impairment in formal office-based tests (Teuber, 1964; Mesulam, 1986). Some authors argue that this phenomenon is particularly associated with lesions in the rostral PFC (Burgess et al., 2000, 2009), hence damage to this region should perhaps be seen as a ‘red flag’, a factor that should alert us to the need to rule out the presence of functional deficits. In 2000, Burgess and colleagues highlighted that patients with lesions in this area often experience impairments with multitasking, with ‘complex behavioural organisation in non-routine situations’ (p.501) and online monitoring (Gilbert et al., 2006). Conversely, their performance on traditional neuropsychological tests of intelligence and memory is relatively unaffected.

Various hypotheses have been put forward in an attempt to characterise the processes that give rise to the frontal lobe paradox. Duncan (1986) suggested that these patients’ functional impairments stem from a defect in goal-based search, ‘a failure to constrain the choice of action by its intended results’ (Duncan 1986, p.285). Others have emphasised the distinction between well and ill-structured tasks (Goel & Graftman, 2000). In a well-structured task, the goal state, set of appropriate responses, and criteria by which to evaluate whether the goal has been achieved are clearly specified. Most office-based assessments are of this type. By contrast, ill-structured tasks typically lack well-defined criteria for evaluating whether the goal has been met and they may be open-ended in the sense that it may not be obvious at what point the task has been completed. This might be more characteristic of tasks encountered in everyday life.

To summarise, patients with PFC damage might perform well on standard tests for the following reasons:

- They can perform tasks which are externally prompted by an assessor, but lack the ability to self-initiate those tasks when they are not cued to do so.
- They have difficulties with ‘complex behavioural organisation in non-routine situations’ (Burgess et al., 2009, p.501). They therefore perform adequately in well-structured office-based tasks, in which the task rules and requirements are clearly set out, but not in ill-structured tasks that occur in everyday life, where the task requirements are less clearly defined and there are no clear rules.
- They lack insight into their impairments, and therefore fail to make use of resources and compensatory strategies.
- Problems with long-term ‘rule maintenance’ may go undetected because the testing process is short (Manchester et al., 2016).
- Testing can fail to reveal the greater effort that is required by people with executive deficits; they may perform normally but be exhausted by it (Manchester et al., 2016).
- There are few demands on social cognition (Jackson et al., 2014).

For all of these reasons, Wood and Bigler, 2017 stress that it is ‘unwise, even negligent, to form opinions on how test performance is likely to influence everyday behaviour, without carefully interviewing those with direct experience of the person’s real-world behaviour over a period of time’ (p.93).

The authors would argue that the same applies to MCA (2005) assessments. The bottom line is that an interview setting may serve to mask an individual’s care and support needs. A structured interview may help people with executive deficits to compensate for their problems (Holloway et al., 2014). Another concern is that capacity is measured in the abstract with this approach; it is the individual’s stated intention that is assessed, rather than their actual functioning (Holloway et al., 2014). If we are to begin to address this issue,
we must consider how we are going to support a change in the MCA assessment process to ensure that information about patients’ adaptive behaviour is gathered as a matter of routine. This is an imperative because it is often others, rather than neuropsychologists, who have the final say when it comes to determining an individual’s mental capacity to make life-changing decisions.

The flaw in the current legislation
In many cases, the most influential MCA assessments are conducted by the ‘decision maker’ (Office of the Public Guardian, 2009). These are typically professionals from the local authority; social services care managers or Deprivation of Liberty Safeguards (DoLS) assessors. They are the final arbiters and they can overturn the outcome of MCA assessments that have been conducted by others.

Local authority care managers are the decision makers when it comes to determining a patient’s need for post-discharge care and support. The role of DoLS assessors is to conduct an independent assessment of an individual’s mental capacity to consent to being in a care home or hospital and to determine whether they have met the two stage ‘acid test’ (Department of Health, 2015) of being subject to continuous supervision and control. Their remit is also to decide whether or not the individual is free to leave, with a focus upon how those who care for them would react if they did leave (The Law Society, 2015). A miscalculation in either of these assessments can result in a failure to provide an individual with appropriate support or safeguards.

It is not unusual for a DoLS assessor or care manager to conduct one-off unilateral MCA interviews. In many cases, it will represent the first time that they have met the patient. Joint MCA assessments are recommended within the legislation where a specialist opinion is called for. However, the anecdotal evidence suggests that this does not happen routinely. The concern here is that whilst these professionals often have considerable experience in conducting MCA interviews, they may lack specialist expertise in assessing people with neurological conditions. More to the point, they may never have come across the puzzling contradiction that we are discussing within this paper. Worthington (2012) has highlighted that a lack of understanding in this area can, at the very least, result in a failure to meet the needs of a patient. He notes, ‘The manifestations of executive dysfunction are typically misunderstood in the community, with the result that many people fall by the wayside or come to the attention of psychiatric or forensic services’ (Worthington, 2012, p.370). In the context of MCA assessments, other professionals can deem patients to be much more competent and self-sufficient than they actually are. This gives rise to the scenario whereby some patients who lack the mental capacity to appraise their care needs, are deemed to be fully capacitous.

Understanding the perspective of non-neuropsychologists
As previously outlined, the dissociation in patients’ performance is a complex and perplexing phenomenon for others to understand. It is unique in that it presents a false façade of competency that belies the severity of the individual’s impairments. Burgess and colleagues (2009) point out that these patients may display an ability to form a plan and remember their actions. They also may present with intact insight because they can

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1 The Mental Capacity Act Code of Practice (4.51):

"Anyone assessing someone’s capacity may need to get a professional opinion when assessing a person’s capacity to make complex or major decisions. In some cases this will simply involve contacting the person’s general practitioner (GP) or family doctor. If the person has a particular condition or disorder, it may be appropriate to contact a specialist (for example, consultant psychiatrist, psychologist or other professional with experience of caring for patients with that condition). A speech and language therapist might be able to help if there are communication difficulties. In some cases, a multi-disciplinary approach is best. This means combining the skills and expertise of different professionals" (p.59).
often say what they should have done when questioned about their errors on tasks or about behaviours that could place them at risk. The key problem that they 'do not do what they said they intended to do' (Burgess et al., 2009, p.501).

It is easy to see why professionals can overestimate these patients' mental capacity to make certain decisions. A lack of consensus needs to be handled sensitively because it can lead to a schism and ultimately an impasse. Local authority professionals and those from third sector organisations, such as advocacy services, have tended to react with concern and even suspicion when the authors have explained that they cannot take a patient's self-report at face value, i.e. that the patient cannot reliably report on their difficulties and care needs. In some cases, they have responded by suggesting that a discrepancy between their MCA assessment findings and ours reflects a difference in ethos. For example, two local authority staff recently misinterpreted concerns raised by one of us as reflecting a level of overprotectiveness and risk aversion that is emblematic of the medical model. This was seen as something that needed to be resisted as it threatened the patient's independence.

They later explained that they have been trained to focus upon empowerment of those under their care and that this is characterised by a move away from a deficit-orientated, towards a more strength-oriented approach. This is seen within the social work literature as allowing people 'not to be seen as passive, helpless victims to be rescued but instead as a self-empowered person fighting abuse/ oppression; a fight, in which the social worker takes the position of a facilitator, instead of the position of a rescuer’ (Adams, 2008, p.12). This position is of course also advocated by the MCA. Indeed, the act is intended to be enabling for people who lack capacity, rather than be restrictive or controlling (Bishop, 2013). A particular safeguard is that any best interest decision must represent the 'least restrictive option'.

At its heart, our local authority colleagues' position was driven by a belief that they were acting in the best interests of the patient. However, in the context of the frontal lobe paradox, 'empowering' some patients may inadvertently increase their risk (Norman, 2016). As previously stated, a cruel feature of this presentation is that it can rob people of their ability to recognise their failures in everyday life. This is explained by the fact that the brain regions that subserve executive functions also play a role in awareness and metacognitive skills (Bivona et al., 2008; Fleming & Dolan, 2012). Problems in these areas are mutually sustaining and it is for this reason why some patients never develop full insight into their difficulties.

It is perhaps important to acknowledge at this point that not all neuropsychologists get it right when it comes to MCA assessments. According to Wood and Bigler (2017) some of us may also be falling into the trap of forming an opinion about an individual's capacity on the basis of an interview. They note: 'Unfortunately the approach adopted by many neuropsychologists is to focus on what a person states they will do, without taking into consideration observations from relatives and significant others about the actual behaviour of the person in real life' (p.93).

In an attempt to mitigate the risk of this, one of the authors of this paper has designed a template to guide assessments (please contact melanie.george@nhs.net if you would like a copy). This prompts assessors to compare the patient's self-report regarding their competency in completing everyday activities, with the accounts of those who have observed their actual functioning. To date, this has mainly been used by occupational therapists.

**Professional guidelines**
The British Psychological Society (BPS) produced interim guidance around assessing mental capacity when the MCA first came into effect (BPS, 2006). A number of other professional bodies (British Medical Association, 2017; Social Care Institute for Excellence, 2017) have also published guidelines. An
unfortunate omission that runs throughout all of these is that they focus exclusively upon the content of the interview. To the authors' knowledge, no guidelines underscore the need to rule out a discrepancy between the patient's self-report and their adaptive behaviour.

At first glance, this would appear to indicate that specific MCA assessment guidelines are required for patients with neurological conditions. However, this would run the risk of failing to ensure that other vulnerable groups are adequately assessed. For example, one of the authors has seen several people with functional deficits and anosognosia, secondary to diabetes-related cognitive impairment. In a particularly memorable case, a succession of local authority assessors deemed one such patient to have the mental capacity to make a decision about his discharge home. This led to protracted disagreements with the impatient team, which was only settled when an independent expert brought in at the behest of the Court of Protection (CoP), agreed with the assessment of the clinicians. Again, the issue was that the individual's problems were camouflaged by his proficient language skills and by his lack of insight. A misclassification of his mental capacity could have proved fatal because it would have resulted in him being discharged home with insufficient medical oversight. The patient had impaired hypoglycaemic awareness, coupled with diabetes that was so poorly controlled that medical staff warned that he would die in the absence of 24 hour medical supervision.

This case underscores the serious consequences for patients that can result from a disparity in professionals' opinions. Ultimately and as in the aforementioned case, the only way to resolve this is to make an application to the CoP and ask them to arbitrate. However, this can delay a patient's discharge from hospital or residential setting for many months. This is clearly not the least restrictive option and can be harmful. We evidently need to find a better way to address this.

The most productive way forward is surely to collaborate with our counterparts within the social work profession. Indeed, some important groundwork has already been laid. In 2016, the 'British Association of Social Workers' (BASW) in collaboration with 'The Brain Injury Social Work Group' (BISWG) produced a helpful document entitled Practice Guidelines for Social Workers Working with People with an Acquired Brain Injury. Although these are generic guidelines and do not specifically address MCA assessments, they are an important step forward. The following quotes are particularly relevant:

'Not relying on the account of a person with an ABI may seem to conflict with the principles of the Mental Capacity Act but people have more control over their own lives, and people's right to make their own choices has to be balanced against their capacity to do so' (p.3).

'Apply the social work skills of advocacy – this is particularly important as people with a brain injury may lack insight into their situation and their capacity and may say they don't need help, when they do. This lack of insight can lead to people not getting the support they need' (p.4).

Conclusion

Differences of opinion regarding the outcome of Mental Capacity Act (2005) assessments can have a profound impact upon the lives of people with whom we work. The stark reality is that this may place them in situations of high risk without adequate safeguards being put in place. The frontal lobe paradox disproportionately increases the risk of this happening.

A key barrier to mitigating the risks associated with this issue is that it is little known outside of neuropsychology. This gives rise to a 'double whammy' whereby most professionals but also the patients themselves are unaware of the problems. This patient group is in particular need of advocacy and support. However, for reasons outlined in this paper, they are often the least likely to receive it.

We must support our local authority colleagues in their efforts to gain awareness of the manifestation of PFC damage. For our
patients' sake, knowledge in this area cannot be the sole preserve of a select few.

**Recommendations**

- High ecological validity should only be assumed when data from executive tests are consistent with ratings from clinicians and significant others. In the same way, MCA assessors should check the veracity of an individual's self-report by ensuring that it is congruent with their performance in everyday life. **Collateral information should be sought from clinicians who have conducted functional assessments and family members.**

- One assessment approach which may be particularly sensitive to problems with metacognition and insight is the discrepancy between the reports given by a patient and those given by caregivers or relatives on an instrument such as the Dysexecutive Questionnaire (Burgess et al., 1998).

- We understand that the BPS Advisory Group on Mental Capacity is in the process of reviewing the guidance issued by the society. We urge the Advisory Group to include in the new guidance, consideration of adaptive behaviour as part of the assessment process. We are also aware that the BPS is commenting on the draft NICE guidelines on Decision Making and Mental Capacity and see this as an opportunity to bring these concerns to a wider audience.

- We recommend that collaboration with groups such as BASW and BISWG may be useful in terms of wider dissemination of information. The BPS has previously collaborated with the Royal College of Psychiatry and this model could be used with other professional bodies.

- It may be helpful for neuro-specialist teams to provide copies of the *Practice Guidelines for Social Workers Working with People with an Acquired Brain Injury* document to their local authority colleagues. This might be particularly beneficial for newly qualified staff or staff who do not have much prior experience of working with people who have a brain injury or other neurological condition. This can be accessed via the following website: [http://cdn.basw.co.uk/upload/basw_61258-5.pdf](http://cdn.basw.co.uk/upload/basw_61258-5.pdf).

- The Brain Injury Needs Indicator (BINI) is another helpful resource for social workers that has been developed by the Brain Injury Rehabilitation Trust (BIRT). Interested professionals can apply to access the BINI as a free digital download via the following website: [https://www.thedigigroup.org/brain-injury/for-professionals/resources/the-brain-injury-needs-indicator-bini](https://www.thedigigroup.org/brain-injury/for-professionals/resources/the-brain-injury-needs-indicator-bini). BIRT describe the BINI as 'a free tool that has been designed to be used by social workers or other assessors during a social care assessment, for the purpose of finding out how well someone has recovered from their brain injury and to determine what social care support they might need'. The BINI is referenced in the Care Act guidance (point 6.43).

- The neuro-specialist team, within which one of the authors worked, found it helpful when a 'link' local authority care manager was assigned to the service. This fostered cohesive relationships between the two teams. It might be worthwhile if other services explore the possibility of a similar arrangement with their local authority.

- The local authority link worker reported that she benefited from attending regular CPD events that were organised by the team. These helped her to build upon her neuro-specialist knowledge and expertise. During the time that she was assigned to the team, there were fewer disagreements regarding patients' care needs. This ultimately improved the consistency of care for patients. Joint training events for NHS and local authority staff are in keeping with the government's drive for closer integration. It is therefore an opportune time to commence these.

- One example of a valuable CPD event would be to develop a brain injury-specific MCA assessment template in collaboration with local authority professionals.
Acknowledgements
We are grateful to Dr Don Brechin, Dr Camilla Herbert and Dr Mark Holloway for their comments on this paper.

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