

Staff Perceptions and Capability in using the Mental Capacity Act to Assess Decision Making in those with Acquired Brain Injury and Executive Dysfunction

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Abstract

The purpose of this article is to establish the perceptions and capability of social care professionals (SCPs) in using the Mental Capacity Act (MCA) 2005 to assess decision-making capacity in those who have executive dysfunction and issues pertaining to the frontal lobe paradox, in comparison to health care professionals (HCPs). HCPs and SCPs from inpatient and community neurorehabilitation teams, social care teams and a best interest assessor team were contacted via convenience sampling and participated in semi-structured interviews. Data from these consultations were analysed using a form of thematic analysis known as template analysis. Four over-arching template themes were identified: 'assessment structure', 'implications of brain injury', 'professionals' capability/expertise' and 'consent, self-report and mental capacity'. The findings suggest that SCPs would benefit from bespoke practice guidance designed to help with the application of the MCA with the acquired brain injury/long-term neurological conditions population—particularly where there is a concern about a person's ability to understand, apply or use information outside of an assessment or supportive conversation.

Keywords: brain injury, executive function, frontal lobe paradox, health professionals, Mental Capacity Act, social care professionals

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Introduction

It is estimated that 14.7 million UK citizens have a long-term neurological condition (LTNC), with 1.1 million of these being sudden onset (such as acquired brain injuries (ABIs)) and with figures rising steadily each year (The Neurological Alliance, 2014, 2019). Common complaints after an ABI include physical, cognitive and emotional difficulties (Mateer et al., 2005; Turner et al., 2007). Cognitive difficulties can include memory, information processing, language, visuospatial processing, fatigue and executive functioning problems (Halligan and Wade, 2005; Rabinowitz and Levin, 2014; The Brain Injury Social Work Group [BISWG] & British Association of Social Workers [BASW], 2019). Executive functioning describes a wide range of higher level cognitive functions thought to be mainly situated in the frontal lobes; for example insight, attention, planning, organisation, initiation, ideas generation, inhibition, control of behaviours and emotions, problem-solving, evaluation, judgement and decision making (Maas et al., 2017). These cognitive impairments, particularly executive dysfunction, cause the main real-world difficulties that those with ABIs face (Knox et al., 2015; Holloway, 2017) and, due to their subtleties, can be hard to quantify (Manchester et al., 2004). Even the best neuropsychological assessments do not assess executive (dys)functioning well due to issues with ecological validity (Sbordone, 1996) and fractionation (Burgess et al., 1998). Tests generally only measure one/some of the cognitive processes under the executive functioning ‘umbrella’ rather than the whole raft of executive functions and complex interplay with other cognitive abilities. Meaning, some people may perform well on tests, but poorly in the real world. This is further compounded by the impact lack of insight (an executive skill) can have on Mental Capability Act (MCA) assessment interviews.

Insight, or awareness, is suggested by Crosson et al. (1989) to have three levels, each of which builds upon the previous. ‘Intellectual awareness’ is where someone has knowledge that they have a deficit (e.g. a memory problem). ‘Emergent awareness’ is where they additionally recognise that they need to use a strategy (e.g. a diary) in the moment, but cannot effectively implement it despite knowing its value and ‘anticipatory awareness’ is being able to anticipate the problem in advance and effectively implement a strategy to minimise the consequences of the deficit (e.g. effectively using a diary to minimise memory issues). More recent models such as the Dynamic Comprehensive Model of Awareness (DCMA; Toglia and Kirk, 2000) suggest that, rather than being hierarchical, awareness processes are dynamic in nature and dependent on situational context. Toglia and Kirk suggest there is ‘offline’ metacognitive awareness (knowledge of a deficit, knowledge and beliefs of personal capabilities) and ‘online’ awareness that can only be measured in a

functional context (i.e. during an actual task). Online skills include task appraisal, self-monitoring performance and self-adjustment as a result of this feedback. In both models there is the understanding that someone can show aspects of awareness (e.g. perhaps only intellectual awareness, or the offline processes of the DCMA) whilst still having a self-awareness deficit as anticipatory awareness, or online thinking/acting, is required for full insight.

This all means that a person may be able to function well within a structured interview, saying all the right things ('talking the talk'—acknowledging a deficit, saying what they could do to navigate it), then behave completely differently in a real-world setting ('walking the walk'—being unable to adjust in the moment). This can particularly be the case if the interviewer does a lot of executive 'scaffolding' during the MCA assessment interview (e.g. generating the ideas, defining the decision, compensating for memory and attentional deficits). In this scenario the client may be deemed to have 'capacity' when they do not. That is, the capacity is artificially created during the interview, but has no functional impact. It is honourable for professionals to be concerned with being unnecessarily paternalistic in these situations, or concerned about subjecting clients to a higher level of assessment than those just assessed verbally. However, the authors wish to highlight that 'insight' as described in the ABI literature is not related to a difference in opinion between clinicians and clients, but to do with a measurable gap between saying and doing 'caused by the very nature of the ABI'. This notion of being able to 'talk the talk, but not walk the walk' is a specific neuropsychological presentation known as the 'frontal lobe paradox' (Walsh, 1985). Completing an assessment with a functional component is therefore not imposing a higher threshold or more rigorous examination, it is applying the correct examination according to the condition.

Skill deficits in the application of knowledge in real-world settings have significant implications on the capacity assessment process. This is because, although one of the MCA criteria is an individual's ability to 'use or weigh' information as part of an informed decision-making process (Department of Health [DoH], 2005; Mantell, 2010), capacity assessments commonly take the form of interviews (Owen *et al.*, 2017). However, in the situations being discussed, a purely interview-based assessment would mask the individual's deficits. A question-and-answer process cannot elicit the information required because of the very nature of the ABI impairments. If assessments are purely conducted in this structured way, they can create a dangerous, false sense of 'capacity' (Lennard, 2016). Triangulation with 'real world data' is therefore paramount; something that is made clear within the National Institute for Health and Care Excellence (NICE, 2018) NG108 guidelines. This is known as the 'articulate/demonstrate' method; requiring the person to articulate how they would make an informed decision within an

interview setting and demonstrate this in practice through engaging in functional assessments and observations of skills at multiple time points. This should be integrated with third party evidence, such as interviews with those who know the person well, obtaining professionals' reports and neuropsychological assessment results (Naik *et al.*, 2008; Holloway and Fyson, 2016; Lennard, 2016; George and Gilbert, 2018; NICE, 2018; 39 Essex Chambers, 2021).

Quality requirements from the DoH (2005) detail that those with LTNCs need to have their specialist needs met when receiving any care/treatment in a health/social care setting, including consideration of needs arising from cognitive impairment. However, there is a paucity of social care literature on the topic, and limited data about the social care needs for these individuals (Mantell *et al.*, 2012; The Neurological Alliance, 2019) and their experiences of interacting with social care (Holloway and Fyson, 2016). Mantell *et al.* (2018) reviewed the literature published by social workers about supporting those with ABIs and identified only 115 articles over a forty-year period (1975–2014). Holloway and Fyson (2016) corroborated these low figures, finding only four articles published within the last decade when searching with the terms 'social work' and 'brain injury' or 'head injury'. In terms of social care-specific guidance, The Adult Social Care Outcomes Framework 2018/19 (DoH and Social Care, 2018) has no mention of 'brain injury', 'head injury' or 'neuro' despite reference to other groups of social care users. Positively, The Care Act (DoH, 2014) and BISWG and BASW (2019) both reference brain injury and cognitive impairment (with BISWG and BASW highlighting that capacity assessments may need to be conducted with this population). However, neither of them provide the depth required to support professionals to give adequate consideration to the unique challenges in this population.

A particularly pertinent paper by George and Gilbert (2018) proposes that individuals with frontal lobe damage may perform well in capacity assessment settings, but struggle in real-life settings due to the frontal lobe paradox arising from executive functioning issues. Similar to other recent research (Holloway and Fyson, 2016; NICE, 2018; 39 Essex Chambers, 2021), it lays out a number of recommendations to support professionals/services working in this arena. For example, making use of real-world observations, using informant-reports (as well as self-report), making use of neuropsychological assessment results, having a 'link' social care worker assigned to neuro-specialist teams or use of the Brain Injury Needs Indicator (Brain Injury Rehabilitation Trust, 2014) as a helpful tool for social workers not familiar with brain injury. However, despite good recommendations as to what may be useful for professionals, the George and Gilbert (2018) paper was published in 'The Neuropsychologist' and is therefore unlikely to be read by the audience being targeted.

It would therefore not be surprising if this group of professionals were not well versed in the common deficits noted in this population, or how to best work with these individuals (Simpson *et al.*, 2002). When paired with the social care model, which has an ethos of empowering individuals and utilising a strengths-based approach, this lack of understanding can have significantly detrimental consequences of: schisms between health care professionals (HCPs) and social care professionals (SCPs) (with those highlighting difficulties with empowerment being labelled as risk-averse or paternalistic), missed vulnerabilities and individuals being wrongly assessed as having mental capacity (House of Lords, 2014, Flynn, 2016; Norman, 2016; George and Gilbert, 2018).

Despite the above, there are no known studies to date that have explicitly researched SCPs' experiences of completing capacity assessments with those with ABIs, particularly in the context of the frontal lobe paradox. This study therefore aimed to establish SCPs' perceptions and capability of using the MCA 2005 to assess decision-making capacity in those with executive dysfunction and issues pertaining to the frontal lobe paradox, in comparison to HCPs.

Method

Ethics

The Health Research Authority online decision tool determined that this research did not require review by an National Health Service research and ethics committee. However, the authors acknowledge the importance of honest, transparent and ethical research and applied ethics-in-action. Prior to interviews commencing, the aims and intent of the research were clearly outlined to participants, risks and benefits discussed and the chance to ask questions given, to ensure informed verbal consent. Participants were aware that involvement was voluntary and that they could withdraw at any time. Data confidentiality was ensured through secure storing of data in-line with General Data Protection Regulation principles and password-protected files.

Inclusion criteria

Six teams were selected via convenience sampling and approached regarding staff consultation. Teams were included that: worked with individuals with an ABI/LTNC, frequently came across issues of capacity and conducted capacity assessments related to a variety of decisions. However, only five groups were able to meet within an appropriate timescale. One team had difficulty with their schedule and so were

Table 1. Professional make-up of staff groups

Staff group	Professionals	<i>n</i>
Best interest assessors	Best interest assessors ^a	6
Older people's social care team	Social workers	16
Physical disability social care team	Social workers	14
	Total SCPs	36
Inpatient neurorehabilitation unit	Head of care, ^b OT, Physiotherapy, Clinical psychology, SaLT	8
Paediatric community neurorehabilitation team	Clinical psychology, Psychiatry, SaLT	4
	Total HCPs	12

^aSCPs.^bNurse professional.

SaLT: speech and language therapy.

excluded on this basis. Consultation was therefore held with forty-eight participants across five staff groups, comprised a variety of HCPs and SCPs (see Table 1) to enable comparison between professional groups.

Interviews

Consultations lasted approximately an hour and used a semi-structured interview approach. The interview schedule comprised of two fictional case studies of people with executive dysfunction who lacked/had questionable decision-making capacity for the scenarios described (drawn from authors' professional experiences), with prompt questions attached and then a further eight questions. A minimum of two authors were present for each consultation, recording discussions and prompting for clarification when required.

Data analysis

The authors wished to take an inductive approach to the data. Post-consultation the primary author therefore conducted a form of thematic analysis known as template analysis. Braun and Clarke's (2006) guidelines for thematic analysis were followed, and the following procedure used, as adapted from King (2012): The primary author immersed themselves in the data with an initial read through of the first three consultations, looking for emerging themes and organising data into potential higher order themes and sub-themes. The remaining consultations were then coded according to this initial template, with the template and themes revised based on how well subsequent data fit with this. Hierarchy of themes was developed through grouping of similar quotes in the data. In order to maintain qualitative rigour, the second author then corroborated themes and data clusters according to the coding

template. Further revisions to the coding template were established post-second author review, including revision of themes. The primary author then re-reviewed data on this basis to achieve theme saturation. Saturation was defined as the point when no new emergent data themes were identified. At this point analysis was concluded.

Template analysis is suggested to be good for group/team data and small data sets (King, 2008). A rich description of the entire data set was aimed for as suggested by Braun and Clarke (2006) to be useful for under-researched areas or those where participants' views are not well known. The authors felt the structure and use of a priori theme/s would be useful and so adopted a subtle realist approach (see e.g. Hammersley, 1992) to the template analysis. The authors focused on individual experiences being described within the data, with the coding template being generated using a 'bottom-up' approach. Due to the small data set it was decided that only semantic themes would be identified. There was no disagreement on themes using this process.

Limitations

Prior to consultation some staff groups had explicitly requested support in completing capacity assessments with those with ABIs/LTNCs due to not feeling competent with such, and two authors had pre-existing knowledge of two teams' viewpoints due to currently/previously working in one of the teams. It is acknowledged that some participants may have been influenced to take part specifically due to one of the interviewers having been a colleague in one of the teams. Steps were taken to mitigate this through not having that person conduct their interview. Authors' biases were managed through blind coding of interviews to check interpretations correlated.

Findings

Template analysis

After template analysis was completed themes emerged from the data as shown below (see Table 2).

Assessment structure

Understanding of the MCA principles and capacity assessment framework

There was variability in understanding of the MCA principles and capacity assessment framework across both HCPs and SCPs, in particular in

Table 2. Final coding template

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1. Assessment structure
 - 1.1 Understanding of the MCA principles and capacity assessment framework
 - 1.2 Question/assessment construction
 2. Implications of brain injury
 3. Professionals' capability/expertise
 4. Consent, self-report and mental capacity
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Key: Higher order themes, sub-themes.

relation to the 'use' component of the 'use or weigh' criteria of the MCA 2005. The majority of professionals were able to recognise that there was difficulty with the person applying skills in practice in the case studies and that these were therefore 'difficult cases' (SCP2), but some struggled to determine how the MCA would apply in these situations, or what they as assessors could do.

The real problem is we are not there when he is doing these things, so what can we do? (SCP3)

The problem can be in situations like this, is we are not seeing the problems, yet we are the ones doing the capacity assessment because it's complex. (SCP18)

Some professionals confused the 'decision-specific' and 'time-specific' nature of capacity assessments, believing that you could only base capacity assessments on immediate conversations, rather than being able to incorporate observation and evidence provided by other professionals/interested parties as part of the 'use' component of the MCA. There was also difficulty noted in how to proceed when there was a conflict between the persons own self-report and arising contrasting evidence.

The problem with capacity assessments is they are focused on the here-and-now at the time of the assessment. (HCP4)

The struggle here is the decision and time-specific nature of the MCA, especially when the person can talk the talk, but not walk the walk. I am not sure how flexible the MCA is when we are faced with situations like this. (SCP18)

However, a small proportion of HCPs and SCPs could identify the 'use' component of 'use or weigh' (MCA 2005) and appreciate the use of real-world observation and assessment to determine this. Although variable, HCPs generally demonstrated greater recognition of the functional nature of decision making in action, rather than relying solely on verbal output.

...when we are faced with these borderline cases, especially when it applies to the person's ability to 'use' the relevant information, we may need to 'test' their capacity.... (SCP33)

We would want to undertake actual world observations. (HCP12)

Subsequently, there were discrepancies within and between groups as to whether the individuals in the case studies demonstrated capacity. One SCP stated that ‘it’s just an unwise decision’ (SCP21), whereas another highlighted that ‘I would be very clear with him...I do have reason to doubt his capacity’ (SCP34). The MCA capacity assessment framework was stated as reasons why the fictional cases either had or did not have capacity:

[Despite lacking executive functioning skills] He would pass a capacity assessment as he can understand, retain and reason. (HCP1)

...We are going to really struggle to say he lacks capacity, even if he does because in the moment [during discussions] he can understand, retain, weigh and will communicate that he doesn’t want our support. (SCP6)

...the evidence suggests that he can’t ‘use’/‘apply’ the relevant information in the real world... (SCP34)

Question/assessment construction

HCPs and SCPs noted that exploring a person’s ability to make an informed decision depends heavily on how the capacity assessment is constructed. In order to construct suitable questions both HCPs and SCPs felt that the professionals involved would need to have knowledge of pre-morbid ability level and behaviour. However, HCPs felt this was important as a method of comparison for assessment, whereas SCPs saw this more as a way to engage the individual.

In cases like this we would firstly need to understand past actions and compare them to current actions/behaviours. (HCP2)

Engage him on a personal level... and [use that] to draw on his personal experience and skills that he does have. (SCP1)

HCPs determined that an important consideration is how the question is posed and framed within the context of one’s cognitive impairments, with provision of suitable cognitive strategies to maximise the individual’s chance of achieving capacity. They implied that, in order to construct appropriate questions, one would need to have cognitive assessment information.

It’s how one focuses the conversation with the person – not just the here-and-now, but imagining actual scenarios based on already identified deficits. (HCP1)

Assess whether the brain injury is having continued impact on his executive functions, and to then consider strategies that could support him if there were potential deficits. (HCP10)

Although consideration of brain injury was discussed by SCPs (see 'Implications of brain injury' theme) it was not discussed as a pre-cursor to identifying cognitive strategies useful for maximising their client's potential to achieve capacity during an assessment.

In order to ascertain the difference between those who may have executive dysfunction and issues pertaining to the frontal lobe paradox and those who do not, HCPs suggested that they would want to 'undertake actual world observations', (HCP12) giving examples such as a 'kitchen assessment' (HCP12), or 'walk[ing] through some example scenarios' (HCP9). Some SCPs similarly discussed that, although they may start out using a 'traditional' capacity assessment methodology of questioning the individual, the use of real-world 'tests' may be required due to the client's presentation. Some examples of functional assessments and role plays were given, similar to the examples provided by HCPs.

Many capacity assessments, as the title suggests, start with an assessment, which is a supportive process. However, when we are faced with these borderline cases, especially when it applies to the person's ability to 'use' the relevant information, we may need to 'test' their capacity. (SCP33)

I would want to set up an OT kitchen assessment to actually observe him prepare food, because the evidence so far suggests he can make the decision when we are chatting, but what about actually putting the words into practice...the evidence suggests that he can't 'use'/'apply' the relevant information in the real world, outside of the assessment. (SCP34)

One SCP additionally highlighted the importance of triangulating information from real-world observations with informant reports.

We need more than just a conversation. We need observations, feedback on others' experiences of working with or supporting the person... It will need to be a holistic assessment. (SCP20)

However, some SCPs, although seeing the relevance of real-world observations, were unable to realise that these could be incorporated as part of a capacity assessment. They stated that they would end up going 'round in circles' (SCP8). A large number of SCPs felt that the 'traditional' method of discussion would be sufficient (without any real world observation).

"...[just] having an honest and frank discussion. (SCP32)

I would want to compare and discuss with him, food related illness before the brain injury...to his food related illness now...to see if he can identify a difference, and to then start to explore with him what those reasons may be...does he feel that the brain injury is still causing him difficulties with managing some day-to-day tasks. (SCP31)

It was suggested by HCPs that inquiring into the individual's wider emotional well-being as part of the assessment would be useful in order to

ascertain whether their presentation may be related to mental health, as opposed to deficits arising from brain injury. It was felt that specialists in the field, over and above SCPs, would be needed in order to follow this line of enquiry.

As this was an assault, perhaps this may be more mental health associated with the impact of the brain injury, so not just the brain injury...social care would not necessarily think about or understand this. (HCP10)

Emotional well-being/mental health was not something reported on by SCPs.

SCPs commented that they recognised that these types of assessments were complex and therefore might take longer than one assessment: 'There would need to be multiple visits' (SCP5). However, they also highlighted that the time constraints within social care services might make this difficult.

One challenge is how much time we can spend on this in the current climate. (SCP34)

Implications of brain injury

Generally, both HCPs and SCPs understood there would be some implications arising from ABI that would be worth exploring, with both considering medical information (such as location of the brain injury) useful. HCPs appeared to have a better grasp of the link between specific brain locations and specific deficits, whereas SCPs were clear that they would need support to understand this.

I would want to know, what part of the brain was affected and specifically how it affects his functioning. (SCP35)

...review[ing] the brain scans to understand whether the brain injury is the cause potentially for the issues. (HCP9)

His frontal lobe is still developing so is this the recklessness of youth or is his decision-making directly impacted by the brain injury? (HCP10)

HCPs expressed interest in a range of cognitive domains that they felt would impact on their completion of a capacity assessment and felt comfortable using clinical terms in discussions, with several references to 'executive functions'. Only two SCPs used the term 'executive functioning.' When asked of the definitions of 'executive functions' or 'insight', those using the terms could not provide one. The majority of SCPs tended to use non-clinical terminology and focused almost exclusively on 'decision making'.

I would want to know about memory, insight, awareness – and this would influence my professional conclusions... (HCP7)

We really need to understand how the acquired brain injury potentially affected the person's decision-making. (SCP24)

One SCP interestingly highlighted that they would not focus on cognitive deficits at all, but would 'focus on a strengths-based approach...' (SCP36) when considering ABI. SCPs in particular made reference to the fact that having a brain injury, despite having implications for being able to demonstrate capacity, is also not evidence of a lack of capacity, highlighting the challenges of these particular cases.

People are allowed to change their personalities after a brain injury. They may just be a different person now, who makes different decisions. This isn't evidence of a lack of capacity. (SCP3)

Acquired brain injury can change personality, but a change in personality doesn't automatically link to an inability to make decisions. (SCP20)

Whilst there is value in this approach, this perspective can bring about its own challenges if the professional is unable to incorporate consideration of deficits into their formulation of the person and construction of the assessment at all.

Professionals' capability/expertise

There was agreement that professional capability was important, but variability between professionals as to who was best placed/'expert' in this arena. All HCPs highlighted that SCPs were competent in conducting capacity assessments; however, as they were not experts in ABI, they would need specialist clinical support in order to conduct competent assessments with this population.

Social workers were experts in assessing capacity...However, they are not experts in acquired brain injury. (HCP3)

It would be unrealistic for social care professionals to determine the person's decision-making skills without the support of appropriately-trained clinical professionals. Especially when faced with these complex/borderline cases. (HCP9)

SCPs largely agreed with this synopsis, though conversely, despite health care colleagues having great faith in SCPs' MCA expertise, some SCPs felt they would not have the knowledge required to reach a 'reasonable belief' in relation to the person's decision-making capacity, especially when the person could 'talk the talk but not walk the walk.'

We would not have the expertise to come to a 'reasonable belief' in relation to her capacity... (SCP11)

With such a complex case...this would be incredibly problematic unless we were supported by another [clinical] professional during the meeting. (SCP1)

It would be easier and quicker if there was a close collaboration between brain injury services and social care services, so we can work collaboratively when these complex cases arise. (SCP34)

Although both groups largely agreed that collaboration was key, HCPs posited that lone capacity assessments by SCPs were common. This led to frustrations around the perceived lack of understanding of ABI knowledge and clinical terminology and how this might adversely impact on capacity assessment conclusions. When attempting to input into capacity assessments/provide alternative viewpoints they described feeling 'blocked' or labelled as 'paternalistic'.

Hard for external practitioners to understand the needs of people with ABI...if we disagree with their conclusion there is often not the option to discuss this and they won't explain how their decisions have been made. (HCP8)

[use of the terms 'executive function/dysfunction' are] problematic when used by professionals without supporting clinical expertise. (HCP12)

When discussing where this 'clinical expertise' would come from, HCPs thought that an MDT approach was sensible, and that clinical psychologists were best placed to support this process due to their competence in the cognitive sequelae of ABI, MCA principles and assessment practices.

They [clinical psychologists] would be better at completing capacity assessments than other professionals. They understand how the acquired brain injury would affect decision-making. I would want to know about memory, insight, awareness – and this would influence my professional conclusions... (HCP3)

A barrier to an MDT approach to capacity assessments involving other teams was purported by HCPs to be that assessments/reports provided by therapists (i.e. SaLTs, OTs or physiotherapists rather than clinical psychologists) were not taken as seriously with 'Therapists tend[ing] to be looked down upon by social care professionals... ' (HCP11).

Conversely, no SCPs referenced psychology input during case study discussions. However, a large number of SCPs highlighted the importance of MDT working with therapists and gave clear examples of where this would be useful. For example, highlighting the need for a collaborative 'OT assessment' (SCP5) and indicating the value of such in coming to well-rounded conclusions.

Such a complex case...would be incredibly problematic unless...supported by another professional. (SCP1)

It should be noted that a small number of SCPs were unclear about where 'expertise' might come from, citing that they were unsure, or offering the 'court of protection' (SCP11) or 'mental health services' (SCP13) as potential suggestions.

Honestly we wouldn't know where to go for expert advice when faced with these types of cases. (SCP8)

Some HCPs described that a dedicated social worker had previously been assigned to their team's cases and this had worked well, leading to a collaborative and well-informed approach. SCPs noted similarly, however, described it breaking down due to feeling alienated by clinical terminology and focus.

It would be great to have a named person to contact where the case involves someone with a brain injury. Not for all cases just the complex ones. (SCP22)

This was tried before, but...discussions were always clinical[ly] focused, limiting the ability of the social care practitioners to engage. (SCP23)

Consent, self-report and mental capacity

This theme only arose in interviews conducted with SCPs, with confusion present over the difference between consent, refusal, self-report and mental capacity. Some SCPs described consent and mental capacity as synonymous. The implications of this are significant, with individuals potentially being deemed to have capacity purely because they acquiesce with a request, have good self-report, or appear to be aware of their deficits, rather than because they have good enough understanding, retention and ability to weigh up and use the relevant information in order to come to an informed decision.

...we say he has capacity if he consents to the support, but if he refuses then we doubt his capacity. (SCP19)

SCPs also appeared confused about whether consent was needed from an individual in order to information-gather from relevant services in relation to capacity assessments. Some professionals stated that without consent they would outright not be able to look into the case, without consideration given to the fact that, if there was a lack of capacity in relation to this decision, then this could be conducted in person's best interests.

Our first job would be to gather info, but this would be incredibly difficult when we don't have the person's consent to gather the information we need. (SCP17)

Discussion

Overall, findings support the research that SCPs do not have an in-depth understanding of the MCA as applied to those with ABIs presenting with executive dysfunction pertaining to the frontal lobe paradox

(George and Gilbert, 2018). HCPs more readily (1) recognised the value of triangulating information from client-based interviews, real-world observations and informant reports, (2) understood cognitive impairments, specifically executive functioning, the frontal lobe paradox and the interplay between cognitive skills, (3) discussed cognitive strategies they would employ to support the client and (4) described feeling clinically competent in this arena. SCPs recognised the difficulty with assessing capacity in these cases, but showed reduced (1) understanding of the MCA principles and capacity assessment framework, (2) understanding of ABIs and cognitive impairments, particularly executive functioning and the frontal lobe paradox, (3) knowledge of where to go to seek specialist support for such, (4) understanding of key terminology (e.g. ‘capacity,’ ‘consent’) and (5) were less sure of their own competence in this area (despite the SCP teams being chosen due to them conducting capacity assessments with these populations).

Some SCPs strongly identified with a strengths-based ethos that is dominant in social care research. The authors would highlight that there is benefit in this approach as there is an equally devastating impact of people having independence removed inappropriately. However, as a result of this culture, HCPs stated that sometimes their opinions were not taken seriously or were over-ridden. This could lead to an impasse between professionals, with health care opinions being seen as disempowering/risk-averse. This fits with themes in the research (e.g. House of Lords, 2014; Norman, 2016; Flynn, 2016; George and Gilbert, 2018) and there is real concern about the potential for a burgeoning schism between professional groups.

Our findings reiterate the conclusions drawn by other researchers. Namely, that professionals with lots of experience of ABI say that weighing up and using is the issue most pertinent to capacity for their clients, but also the aspect of the MCA criteria that SCPs least understood (Owen *et al.*, 2017; Moore *et al.*, 2019). We would echo concerns in the literature (see e.g. Simpson *et al.*, 2002; Holloway and Fyson, 2016; George and Gilbert, 2018) that social care guidance on the use of the MCA for this population is woefully inadequate, being neither specific nor in-depth enough. The implications of this are that, as George and Gilbert (2018) and Owen *et al.* (2017) highlighted, in some cases, capacity assessments are not conducted full-stop, or are insufficiently conducted. Potential vulnerabilities of clients could be missed and individuals could be wrongly deemed as having capacity (House of Lords, 2014; Flynn, 2016; Norman, 2016; George and Gilbert, 2018). This is perhaps best shown in the recent Safeguarding Adults Review of the death of a man with an ABI whose capacity was assumed because he said he wanted no help (Johnson, 2021).

The authors suggest that there are several areas for improvement. First, further investigation into interdisciplinary working should be

explored. There was clear agreement between our findings and the literature that assessments by non-specialist social workers are unlikely to be sufficient (39 Essex Chambers, 2021) as an effective capacity assessment requires specialist knowledge (Holloway and Fyson, 2016). We strongly recommend that social teams that are set-up to support people with ABIs are multidisciplinary rather than unidisciplinary. In lieu of this, having better links between services will provide clarity on which specialist professional should provide this, where SCPs are unsure. Specialist link workers are recommended as beneficial (Headway, 2014; George and Gilbert, 2018) and we would highly recommend establishing a link-worker scheme between local neuro-specialist teams and local authority social care teams.

Similar to research by George and Gilbert (2018) and Odumuyiwa et al. (2019), our research clearly highlighted that further learning and development opportunities are required for SCPs to further understand the needs of those with ABIs. These resources should be designed to help application of the MCA with the ABI/LTNCs population where there is a concern about a person's ability to apply or use information outside of a traditional assessment/interview, i.e. those cases that the MCA (DoH, 2005) describes as 'borderline'. It is imperative that this be co-developed with SCPs and HCPs (as well as legal professionals). The training resources would ideally include:

1. MCA principles and capacity assessment framework, with particular emphasis on the 'use' component of 'use and weigh.' Providing clear and practical guidance for SCPs faced with situations where there are concerns identified by the practitioner, the person's family, friends, care staff or supporting clinical professionals regarding a person's ability to 'use' information outside of a capacity assessment interview. It should aim to show professionals assessing capacity how to assess the validity of the individual's self-report, by comparing this with their ability to apply this in everyday life. Whilst simultaneously applying a strengths-based approach to these conversations congruent with the social care ethos, and meeting the first three principles and empowering ethos of the MCA Code of Practice (DoH, 2005). It should support professionals to understand the importance of clearly identifying and gathering information about any potential inability to 'use' the information in practice and evidencing this, before reaching any conclusion that the person is unable to make the specific decision for themselves.
2. Key papers and guidance in the field. For example, NICE (2018) NG108 guidance on triangulating information and seeking specialist support.
3. Foster conversations about who, how and when to involve other professionals.

4. Guidance on clinical/technical terminology, differences between capacity and consent and effectively recording decisions.
5. Exploration of the plethora of cognitive difficulties that can arise from ABIs, but specifically focusing on executive dysfunction, off-line/online awareness and the frontal lobe paradox. It should cover how the act of undertaking an interview is (of itself) the compensation required for some dysexecutive people to (verbally) be very competent and able, and can provide the scaffolding for capacity to artificially exist within the confines of an interview, but that this competence (capacity) does not exist outside of the interview in a functional context.

We suggest that these training resources would set SCs up with the skills and knowledge to set up interdisciplinary networks in their region. Future interdisciplinary working and training would then serve to strengthen alliances between professionals and minimise the potential for schisms.

Conclusion

This article highlights the importance of better integration of health and social care within ABI settings, better sharing of knowledge and better training for SCs.

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