Mental Capacity and Best Interests

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Do you…

undertake capacity assessments with people who have had a brain injury?

Are the decisions about…

staying in hospital or a care home for care or treatment?

Do the decisions involve…

restrictions like locked doors, individual supervision or medication?

We would love to hear from you!

We are looking for hospital staff (including doctors, ward managers, senior nurses and senior allied health professionals) or Deprivation of Liberty Safeguards Assessors working in the Northwest to try out a tool designed to support complex capacity assessments. Participation will involve trying the tool with around three people who have had a brain injury and sharing your views about it.

Taking part is voluntary and your information will be kept confidential. Your contribution could make a real difference to other professionals and the people they support as services prepare for changes in the legal framework. Please get in touch to find out more by contacting the researcher using the details below.

Thank you

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Aims

- To increase awareness of best practice around the assessment of capacity and documentation of assessments
- To gain an awareness of the factors to consider when assessing capacity
- To gain an understanding of the Best Interest process and how to apply it

Common questions asked regarding mental capacity

- Admission and treatment
- Swallowing
- Consent to relevant medical procedures
- Refusal to eat
- Drinking alcohol
- Going off the ward when on a DoLS
- Consent to sexual relations
- Social media use
- Management of finances and Lasting Power of Attorney
- CHC screening
- Discharge destination and future care needs

Why do we need to assess mental capacity?

- The Mental Capacity Act (2005) brought into legislation ways of acting and making decisions on behalf of adults (over 16 years of age) who do not have the capacity to make the decisions themselves
- This means that it is a legal requirement for us to assess capacity when a decision has to be made and there is a reason to suspect that the person may not have the capacity to make it

Impressions of capacity

- Formal assessments of mental capacity are necessary for decisions that have a significant impact on the person's life, as mental capacity is often not obvious
- Clinical teams' and families' impressions of capacity are usually incorrect but only when the person does not have capacity (Raymont et al., 2004)
- MDT members found it more difficult to identify people without capacity than those with capacity to make a decision about discharge destination (Mackenzie, Lincoln & Newby, 2008)

What do we mean by capacity?

- Capacity refers to the ability to make a decision in relation to a specific matter at the material time (MCA)
- Capacity is not a general characteristic of the individual and does not refer to an assessment of a person's decision making ability in general (Gerhand and McKenna, 2007)
- Capacity can relate to a particular 'process' as well as a one off decision

Principles of the Act

1. A person must be assumed to have capacity unless it is established that he lacks capacity

2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success

3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision

Principles of the Act cont.

4. An act done, or decisions made, under this Act or on behalf of someone who lacks capacity must be done, or made, in his best interests
5. Before the act is done, or the decision made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action

Mental Capacity Act

- Incapacity is presumed to continue until shown otherwise; however, a further capacity assessment is not required unless something has changed, eg, cognition
- Capacity is recognised to fluctuate in some conditions and situations (p.49, DCA, 2007) and so it is necessary to review it
- The assessment of capacity is based on the balance of probabilities rather than making the decision beyond reasonable doubt (p.44, DCA, 2007)
- Remember that the person does not need to *prove* that he/she *has* capacity; the onus is on the assessor to show why the person *does not* have capacity

Who should assess capacity?

- The decision-maker needs to be sure of the person's capacity before they go ahead with the decision; however, this does not mean that they have to assess the person's capacity
- The assessment of capacity can be carried out by someone else who then advises the decision-maker
- This might happen if the decision-maker is not an expert in capacity or in the impairment of mind or brain, eg, brain injury
- Joint assessments are advised for complex decisions, eg, an expert in capacity and an expert in the decision/impairment

Who should assess capacity? cont.

- It is useful to involve experts from the start of the process in complex assessments, rather than asking for an opinion on an assessment that has already been completed
- Remember that the decision is just the professional's *opinion* after completing an assessment
- The Court of Protection is the only body that can decide definitively whether or not someone has mental capacity for a specific decision
- The CoP can be consulted in situations where it is not clear, or there is disagreement, around capacity

Two-stage test

- The Code of Practice for the Mental Capacity Act (DCA, 2007) recommends a two stage model for assessing capacity that combines a status and functional approach (p. 41):

  the person to be assessed must have

1. an impairment of, or disturbance in the functioning of, the mind or brain (temporary or permanent)

   and this must have

2. made the person unable to make a particular decision at the time it needs to be made

How do we assess stage 2 of the two-stage test?

- The factors required to have capacity set out in the Code of Practice (DCA, 2007) are the abilities to:

1. Understand information about the decision to be made:
   - what the decision is and why they need to make it
   - understand the salient information relevant to the decision; which would include consequences of the decision (benefits and risks) and alternatives to the proposed solution, including taking no action or making no decision
2. retain the information; with the period of time required relating to the decision (for sufficiently long enough to make the decision, and with consistency across different time points if memory span is very short)

How do we assess stage 2 of the two-stage test? cont.

3. use and weigh the information to make a decision; which could preclude people with addictions or impulsivity / disinhibition following a brain injury who may understand the consequences but not be able to abate their actions
4. communicate their decision; which may include a simple yes/no answer or consistent non-verbal communication (may require assessment and/or intervention from a SLT)

Ongoing decisions

- Ongoing decisions, such as admission for care and treatment and care needs on discharge, require the person to be able to retain the relevant information over time, not just in the short assessment period, so that they can use the information in the next week or month
- This requires carryover between assessment sessions (it is always better to do more than one assessment session for this reason and for others, such as slow processing speed, unless it is obvious that the person does or does not have the capacity to make the decision)
- For example, if the person needs to stay in hospital for treatment and rehabilitation, and she would be at risk if she self-discharged, then she needs to be able to remember this for the whole of the admission and not just for 10 minutes with prompting during the assessment

Difficulties assessing capacity in people with ABI

- Subtle cognitive problems that can affect complex decision-making in the community
- Issues with insight into their problems – not believing information actually relates to them
- Can repeat information back without having a full understanding of it
- ‘Frontal lobe paradox’ (George and Gilbert, 2018) – “can talk the talk but not walk the walk”, ie, a person can say all of the right things but then not be able to put it into practice, eg, due to initiation problems, impulsivity, disinhibition or problem-solving difficulties
- The structure of a capacity assessment can hide these difficulties (ABI and MCA Interest Group, 2014)

Relevant information

- Have to make sure that the person has the relevant information before you can assess their capacity - preferably in simple language with choices and implications clearly outlined in order to increase the likelihood of the person understanding it - repeat before assessment
- Physicians have been advised to include information on significant or unavoidable risks, even if small; alternative treatments; and risks of doing nothing (DH, 2009)
- 39 Essex Chambers capacity assessment guidance sets out thresholds of understanding from case law (some of which is below)

Thresholds of understanding

- A Court of Appeal ruling (2019) stated that case law is to be used as guidance for capacity assessments and can be expanded or contracted accordingly for the individual
- Several decisions have thresholds of understanding set out by case law, eg, contact with other people, sexual relations and marriage
- Some relevant for health professionals include residence, care and social media use

Thresholds of understanding cont.

- Residence (*LBX v K, L and M* [2013])
  - Type and nature of the living options
  - Broad information about the area
  - Difference between living and visiting
  - Access to activities, friends and family
  - Basic understanding that there is a cost
  - Basic understanding of rules in each place
  - Who you would be living with
  - The care you would receive
  - Risk that family may not visit if you go against their wishes (not presented as permanent risk though)

Thresholds of understanding cont.

- Care (*LBX v K, L and M* [2013])
  - What areas you need support with
  - What sort of support is required
  - Who will provide the support
  - What would happen without support or if support was refused
  - That carers may not always treat you properly and knowing how to make a complaint if you are not happy

Thresholds of understanding cont.

- Social media use (*Re A* [2019])
  - Lack of control over images and information put on social media – others may share them
  - Can limit the sharing of information by using privacy settings
  - Posting or sharing rude or offensive material may upset or offend people
  - Some people may not be who they say they are
  - Some people may pose a risk to you or want to cause you harm
  - You may be committing a crime by looking at, or sharing, extremely rude or offensive material

How do the factors required to have capacity link to cognitive functions?

Factors required to have capacity	Cognitive functions
Understand the decision and why they need to make it	Language, insight, orientation
Understand the information relevant to the decision	Language, insight, attention, memory, executive functioning
Retain the information	Memory
Use and weigh the information to make a decision	Memory, attention, executive functioning, including inhibition
Communicate their decision	Language, including non-verbal

Capacity assessment with cognitive problems

- Look for consistency in responses
- Watch out for suggestibility or acquiescence and try to reduce likelihood
- Do repeat assessments
- Actions to empower the person, whether has capacity or not

Other factors to consider

- Communication level
- Previous attitudes, values and beliefs, eg, beliefs about hospitals, rigid views about issues
- Psychosocial factors, eg, undue pressure from others, acquiescence, lack of assertiveness, deference
- Mental health issues, eg, low mood, anxiety, psychosis

Introducing the assessment

- Use simple terms in conversational manner
- Frame it in a positive way, eg, letting them express their views on the topic, supporting them to make the decision, considering their views and values to see what is in their best interests if they are unable to make the decision themselves
- Tailor it to the individual
- Be clear about the decision in question

Difficulties engaging

- Make sure you are promoting a collaborative approach with the person
- Be flexible and open-minded
- Involve professionals who have a good relationship with the person
- Complete the assessment in an informal manner, eg, having a chat walking round the hospital

Semi-structured interview

- Developed a semi-structured interview for research regarding discharge destination but it has now been adapted for clinical use (Mackenzie, 2005):

1. Establish the actual risks and issues surrounding the decision in question and the relevant information that has been given to the person (use MDT knowledge and skills and family information) before the assessment
2. Assess person's insight into his/her current problems

Semi-structured interview cont. 1

3. Assess other things that may be influencing the person's capacity, e.g., mood and family opinions
4. Directly question regarding actual risks and issues to see if he/she is aware of them and believe them to be related to him/herself - this assesses understanding and retention of the relevant issues
5. Assess memory of and awareness of safety advice

Semi-structured interview cont. 2

6. Assess insight into how problems will affect him/her in a different situation, e.g., when at home
7. Assess risk awareness and problem-solving skills in specific relevant situations
8. Assess ability to take advice and believe the advice of professionals
9. Assess ability to weigh the information by looking at the pros and cons of the alternative options

Semi-structured interview cont. 3

- The whole assessment assesses the person's ability to communicate his/her decisions
- Avoid yes/no susceptible questions if possible. However, if the person has communication problems, turn the question around to make sure they understand both versions
- This assessment can be adapted for other capacity assessments, e.g., finances or treatment decisions

Promotion of capacity

- This is a statutory responsibility under the MCA – A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success. / A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances.
- DDA 1995 – section 49A(1)(d) – Recognises the long standing principle that it is sometimes necessary to take positive steps to overcome the barriers faced by disabled people by making reasonable adjustments (such as providing information in different forms).

Enhancing decision-making

- Simple things, such as picking the best time of day for the person and minimizing distractions, can help
- Breaking it into chunks, using non-verbal demonstrations, quizzing participants and using repetition have also been found to help
- Provide concise, relevant simple information using different media, e.g., verbal, non-verbal, written and pictorial
- Give all of the options available, help list the pros and cons, and use a decision tree

Enhancing decision-making cont.

- Use an interpreter whenever there is a question about the patient's fluency in the language used for the assessment, as the decisions being made often involve complex concepts
- Involve familiar people whom they can trust, such as family and friends, in conveying information and providing support but be careful of family 'interpreting' responses
- Being listened to, a friendly environment, friendliness and familiarity of staff, perceived absence of prejudice, and being encouraged to develop confidence have been found to help people make decisions (Myron et al., 2008)

Understanding Information

Sentences which makes sense!

- KISS – **k**eep **i**t **s**hort and **s**imple -so what is simple?
- One idea per sentences e.g. “The doctor will give you medicine”, “You will go to sleep” rather than “The doctor will give you medicine and then you will go to sleep”.
- Always say what you mean rather than what you don’t mean – **ban** the ‘no’, ‘not’ and ‘n’t’ e.g. “You’re staying in” rather than “You’re not going out”, “The money has all gone” rather than “There’s no money”.

Documentation

- As solicitors are becoming increasingly involved, we need to firm up our procedures and documentation
- Document your assessment and show how you have applied the principles of the MCA
- Write down the questions asked and the answers provided verbatim
- Be prepared to be able to explain your reasoning and rational for your opinion to others
- Fill in official capacity documentation with reference to the interview schedule used

Documentation cont.

- Documentation should include:
  - The decision the person is making
  - The reason the assessment was commenced
  - Threshold for understanding
  - People consulted
  - Support given to make the decision / maximise capacity
  - The diagnostic test of capacity (stage one)
  - Additional factors beyond the skills of the person
  - The functional test of capacity (stage two), including evidence and examples of questions and answers
  - If the person lacks capacity, is it **because** of their impairment of mind or brain?
  - Conclusion
  - Recommendations, even if the person has capacity
  - Attached documentation

Common problems with documentation

- Things often missed off documentation:
  - The level of understanding required for the decision
  - Adequate evidence for each of the four parts of the functional test
  - The ways in which you tried to enhance the person's capacity
  - Stating if the impairment is permanent
  - Recommendations
  - Stating that the lack of capacity is *because of* the impairment

IMCA

- What is an IMCA?
  - An Independent Mental Capacity Advocate
  - They act of behalf of someone who lacks capacity.
- When to consult/instruct an IMCA
  - If there are no interested parties to consult re best interests (e.g. no family or friends)
  - Family disagree with each other as to BI
  - Family disagree with professionals as to BI
  - There is a conflict of interests
  - Concerns about protection/safeguarding of a vulnerable adult

The Best Interests Process

- One of the key principles of the MCA is that any decision made on behalf of someone who lacks capacity must be done in their “best interests”
- The decision-maker is the person who will carry out the action after the decision is made
  - Under the MCA this is the person who ultimately makes the decision after consultation with others
  - There can be different decision-makers for different decisions with the same patient
- It is good practice to hold a Best Interests Meeting if someone were found to lack capacity around a complex decision, otherwise, discussions with all interested parties will suffice

Best Interests Checklist

- **Involve the person** in the process as fully as possible
- Consider the **past and present wishes**, feelings, beliefs and values of the person
- Consider **the views of family members** or other interested parties who are involved in their care or welfare
- Consider the **least restrictive alternative**
- Would it be appropriate to delay the decision?
  - e.g. if they are likely to regain capacity
- Is the person entitled to an IMCA?

Best Interests Checklist cont.

- Is there anyone with the legal right to make the decision – for example, a Lasting Power of Attorney or Court of Protection Deputy?
- Has the person made an Advance Decision to Refuse Treatment that would apply?
- It is also important to consider how the decision might impact on the person's life e.g.
  - Social relationships
  - General welfare
  - Medical welfare
  - Psychological wellbeing

Best Interest Meetings

- Who should be consulted before the meeting or invited to it?
  - Anyone the person has previously said they wanted involved, anyone involved in caring for the person, anyone interested in the person's welfare, their attorney if they have LPA, or deputy (CoP) if they have one
  - The patient's IMCA, if they are entitled to one
  - If you do not consult someone, you must justify why you haven't spoken to them and document this
- It is advisable for the Chair not to be the decision-maker (West and Glover, 2014)
- It is not necessary for the person to attend the whole meeting if it is not in his/her best interests

Best Interest Meetings cont.

- The chair should:
  - Introduce the reason for the decision and outline the options
  - Invite people to discuss the options, using a balance sheet to record to advantages and disadvantages of each option
  - Encourage everyone to take part and prevent domination of any one individual in the discussion
  - At the end, summarise the discussion and invite everyone to give their opinion
  - If they are the decision-maker, make the decision

Best Interests Documentation

- Minutes must be taken in the Best Interests meeting and distributed to all attendees
- Complete official best interests documentation in order to record the decision
- This should include:
  - The decision to be made
  - People consulted
  - Options available
  - How the decision was reached (using a balance sheet approach) and the reasons for making the decision
  - The outcome of the decision and any future review

What happens if you cannot reach a decision?

- If a decision cannot be reached during a meeting or there are disagreements between different parties:
  - Involve an IMCA if you haven’t already
  - Get a second opinion
  - Attempt mediation
  - Consult Safeguarding
  - Court of Protection

Blatant plug!

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- Hopefully out in June 2020!

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