

Yes – but no, but ...

Please bear with me for a while – I need to 'set the scene'.

Recently Celia Kitzinger posted a tweet, which led to this exchange of tweets between Celia and me [Celia and I both agree that healthcare professionals do not currently seem to be applying the Mental Capacity Act 'as it is written' - but Celia tends to explain to lay people what they need to do in order to maximise their chances of healthcare professionals respecting their legal rights, and I am more for changing the dubious behaviour of those healthcare professionals]:

<https://twitter.com/KitzingerCelia/status/996373730283741186>

Interested in finding out how to make an advance decision to refuse treatment? Or how to support others who want to do so? We're running a workshop in York for [@DyingMatters](#) week. All welcome!

Me:

If you manage to get agreement about the issues I raised in <http://www.bmj.com/content/356/bmj.j1216/rr-1> then please do let me know, Celia!

Celia:

I don't expect 'agreement', and am not looking for it. I will support ppl who want to refuse CPR to do so in an ADRT and via a DNACPR form signed by a doctor. This will maximise their chances of not being given treatment they don't want. But I can't guarantee it.

Me:

I agree with everything in your tweet - EXCEPT I DO want agreement on these issues (I'm not willing to say if I 'expect' agreement - just that until there is 'agreement', I'll continue to be a pain-in-the-backside to 'ReSPECT', etc!). And the problems do need highlighting.

Celia:

It really shouldn't be too much to ask for - I'm not sure why it proves so difficult in practice.

A tweeter called Sara, posted this tweet (as part of a longer discussion which I did not look at – I just wanted this one!):

<https://twitter.com/sarasiobhan/status/995735439574265866>

"But the real purpose of this email is about the use, or misuse, of the MCA by 'healthcare professionals', in the Nursing Homes, in the Hospital and by the NHS. It seems that many of these folk don't know what the Act says, don't know how it's supposed to work, or don't care."

I then exchanged some Twitter direct messages with Sara – I asked if she objected to my using the tweet (no objection) and also to using the DMs (again, no objection):

Hi, no objections - I didn't write it though it was part of an email to me :)

I sent

Thanks Sara - it is fantastically-concise description of the problems with the real-world implementation of the MCA, which endless 'official reports' point out using many more words.

And she sent

It so is.

Then I sent

Absolutely - the deeply unsatisfactory thing about the MCA, is that a patient or family-carer can read the MCA itself, and then ONLY TOO LATE 'discover that the professionals seem to have read something completely different'. Totally unsatisfactory state of affairs!

When I tweeted:

https://twitter.com/MikeStone2_EoL/status/997114011681517568

[#havetheconversation](#) But one of the problems with 'advance care planning' is that 'part of the conversation hardly ever happens', surely? <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-end-of-life-question-which-cannot-be-asked-and-its-answer-which-cannot-be-ignored/970/>

See <https://www.dignityincare.org.uk/Discuss-and-debate/download/291/> and I explain that 'I have asked the question' - but I really needed to be pushed -

Sue Forsey tweeted:

Your so right Just told my husband about a local dying matters conference in Taunton reply what the hell? He doesnt want to talk about death especially his!

I tweeted:

I'm not all that keen talking about my own death - I'm much happier analysing NHS EoL behaviour, than I am thinking about my own mortality. And I've just been annoyed by my local community palliative care team this morning (they do not seem keen to talk to me)

Sue tweeted:

I do Mike I don't want to end up in my local hospital where mum died How sad & upsetting is that if I collapse OOH any EOL plan no cpr will be disregarded by paramedics my bones

may be broken & I will be left to the hospital's mercy a terrifying prospect that I have witnessed

And Sue also tweeted:

Our local PC lead has stated in our local paper Taunton Gazette about if a dying PT wants he can be taken in his fav VW for a special journey Beggars belief When his team won't work w/e

Having set the scene – now I will explain the title of this piece

A palliative care consultant, recently sent a question to me: it was a 'conundrum' about the application of the Mental Capacity Act. In effect, the conundrum amounted to this:

'We know that the MCA is a law which applies when decisions are made which affect mentally-incapable patients, who cannot make their own decisions. If a mother is living with very-severe dementia, and definitely cannot make her own decisions about her future healthcare, and if the mother's GP discusses her future care with the woman's daughter, if the GP makes a written record record of the discussion, is that covered by the MCA?

Some of my colleagues, argue that because the doctor writing the note of the conversation is not 'making a medical decision' - because, for example, an out-of-hours doctor would be making the decision when that OOH doctor read the note at a future time – the note is not covered by the law'.

In fact, this one isn't difficult to untangle: the MCA covers 'acts done, and decisions made' and the writing of a note of the conversation, is 'an act done' and therefore is covered by the MCA's best-interests requirements, with the proviso 'if someone other than the doctor who recorded the note, might make a healthcare decision which would be influenced by reading the note'.

The interesting point, is that the doctor who sent me the question, had not figured out the answer. After I sent the answer, and his reply made it obvious that he hadn't worked it out himself, I sent what amounted to:

'You are a consultant doctor, and I'm just a 'bloke off the street' - isn't it embarrassing, that you hadn't figured out the answer, but I could tell you the answer?'

and his reply amounted to:

'I'm ridiculously overworked, and I'm happy to get correct answers from anywhere!'

Now, I became involved in end-of-life debate in 2009, and by about 2012 it was becoming apparent to me that often if I asked nurses, doctors and paramedics questions about the MCA, they seemed to understand the answers less-well than I did. Back in 2012, I would have said the answer to my '... should you be embarrassed' question, was a simple 'yes!'.

But in 2012, I had a decent grasp of the MCA – but I hadn't read anything like as much clinical guidance, clinical 'debate', and court judgements as I have read since 2012. And now, my own answer to that 'should the clinicians be embarrassed' question, would be:

Yes – but no, but ...

I will try to explain, how I got from 'the clinicians really should understand the MCA – they should be really embarrassed if a layman has to explain it to them', to my current 'they should be embarrassed – but, I understand why they struggle with the MCA'.

In other words, I'm going to attempt to answer – and this is not 'evidence-based', it is 'what I have picked up and deduced' - Celia's:

It really shouldn't be too much to ask for - I'm not sure why it proves so difficult in practice.

I will also add: ideally it should be doctors, nurses and paramedics who are writing this piece – it shouldn't really be me.

There seem to me, to be these main reasons, why 'professionals struggle with the MCA':

1) The MCA is a mixture of principle and 'specific' - and the principle is not necessarily easy to apply in many of the real-world situations which HCPs are involved in, and the specifics often complicate, rather than simplify, the working-lives of HCPs;

2) The MCA is a law, and clinicians are interested in treating patients, not in law (read what doctors write about law, and often it very quickly turns into a discussion not of law, but of medical ethics), and whereas doctors are strongly motivated by the principle of 'beneficence' ('doing good') the MCA hardly contains 'doing good' at all;

3) Clinicians have things 'thrust upon them' which are not fundamental concepts within the MCA, and which are an unhappy and often contradictory fit with the MCA: notably 'safeguarding' and 'audit';

4) Even if everyone agreed about what the MCA says [and currently that agreement does not exist], there would still be huge issues arising from ‘perspective differences’.

I will probably not be able to completely separate those four things, but I will use the categories nevertheless.

1) The MCA is a mixture of principle and ‘specific’ - and the principle is not necessarily easy to apply in many of the real-world situations which HCPs are involved in, and the specifics often complicate, rather than simplify, the working-lives of HCPs;

For example, these sections of the MCA seem to be very specific indeed:

6(6) Section 5 does not authorise a person to do an act which conflicts with a decision made, within the scope of his authority and in accordance with this Part, by—

*(a) a donee of a lasting power of attorney granted by P, or
(b) a deputy appointed for P by the court.*

6(7) But nothing in subsection (6) stops a person—

*(a) providing life-sustaining treatment, or
(b) doing any act which he reasonably believes to be necessary to prevent a serious deterioration in P’s condition,*

while a decision as respects any relevant issue is sought from the court.

Whereas this section of the MCA is in essence ‘a description of principles’:

4(6) He must consider, so far as is reasonably ascertainable—

*(a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
(b) the beliefs and values that would be likely to influence his decision if he had capacity, and
(c) the other factors that he would be likely to consider if he were able to do so.*

Not only are the sections of the MCA which describe ‘principles’ much harder to understand than the ‘specifics’ bits, but they will also look very different depending on who is looking at them. I looked at 4(6)(a) and because I usually think about end-of-life, and a patient who is mentally-capable when terminally diagnosed, that ‘present wishes’ was somewhere between not very relevant and ‘a theoretical concept’ - but, it suddenly became very clear to me that clinicians who are working with long-term dementia patients, will view that ‘present wishes’ very differently [and they will find less application of ‘past wishes’ than is the case in my most-analysed scenarios]. 4(6)(b) is easier to apply during many of my end-of-life scenarios – as indeed it was for Mr Justice Charles in ‘Briggs’ - than

during long-term dementia, but when the person is 'obviously still deeply-engaged with life'.

Judges have only recently started to clarify some of the puzzles posed by the MCA (for example, Mr Justice Charles quite recently explained how a best-interests decision which inevitably leads to the person's death can be justified – he was ruling on a coma case, but his argument was exactly the same argument that I had published a couple of years earlier in connection with CPR) and even the drafting of the MCA itself contains an obvious mistake (it mentions attorneys 'consenting to' offered treatments, which isn't technically correct – and it isn't the sort of 'not quite correct' wording which you would expect to find in a law).

There is also, it seems to me, an inherent departure within the MCA from the common distinction between 'treatment' and 'care': the MCA's Code of Practice tends to try and 'introduce' such a distinction, but 'normal family-carers' are not legally required to 'have regard to the code'. And this treatment/care distinction – usually associated with a belief that 'only HCPs such as doctors and nurses provide treatment' whereas other people might provide 'care' - breaks down for some things which are clearly treatments (notably for cardiopulmonary resuscitation which taught as first aid), and also in other really simple situations (for example, a GP believes that a patient living with dementia should be taking a tablet but the patient's spouse would need to be giving the tablet to the patient, and the spouse doesn't agree that the tablet should be given, and refuses to give it).

This amounts to 'there is still a lot of work to be done, before we can claim to have reasonably-satisfactorily 'thrashed out the meaning of' the MCA': but it could be achieved, I hope.

I will point out, it seems obvious that the people best-placed to consider section 4(6) of the MCA, are not the clinical team who understand the patient's clinical situation, but instead are the patient's close family and friends – logically, it seems clear that the MCA 'implies that the people best-equipped to consider an incapacitous person's best-interests are the person's family and friends': which is an example of how 'the MCA complicates the lives of clinicians'. I've explained that in three linked tweets at:

https://twitter.com/MikeStone2_EoL/status/906073527236907009

and as the third tweet reveals, at least one lawyer who works with the MCA agrees with me.

A Court of Protection out-of-hours judge, explained a few years ago to a newspaper, that late one evening some hospital doctors phoned him up. They had a patient who had taken an overdose in an attempt to commit suicide in A&E, but he was refusing to be treated – the judge told the doctors 'he seems capacitous to me – you can't treat him without his consent'. So the man died that night – and, the judge explained 'I did not 'make a ruling' here': which must mean that the doctors had effectively asked the judge to 'tell us that he isn't capacitous' – the judge wasn't doing that, because the MCA assumes capacity [so if the doctors had said 'we claim this patient isn't capacitous, and the judge had then spoken to the patient and said 'I've decided he is capacitous', that would have been 'a ruling']]. But

– while the logic is 'unless we can prove mental incapacity, we must let the patient die', if A&E doctors do that, you can imagine the conversations with bereaved relatives the next day: **'What!!! You could have kept my son alive, but because he told you not to treat him, you let him die!!!'**. So, it is easy to see why the doctors 'feel a need to phone the judge' – even though in theory, the MCA with its assumption of capacity, means they should theoretically be applying 'we can't prove he isn't capacitous, and he is refusing to be treated, so we should let him die'.

2) The MCA is a law, and clinicians are interested in treating patients, not in law (read what doctors write about law, and often it very quickly turns into a discussion not of law, but of medical ethics), and whereas doctors are strongly motivated by the principle of 'beneficence' ('doing good') the MCA hardly contains 'doing good' at all;

The MCA describes the decision-making autonomy of people who have not been 'proven to lack mental capacity', it describes how decisions made during mental incapacity can be justified legally, it explains which people have 'decision-making authority', etc.

But the MCA **doesn't** say that 'the right decisions are those which result in 'good outcomes' – it is framed in terms of the 'information which decision-makers need, in order to make decisions'. Ignoring 'caveats' there isn't any 'beneficence as the guide' in the MCA's concept of Informed Consent, and its Best Interests seems to exclude 'beneficence' from 'genuine best-interests decisions' and to only allow for concepts related to beneficence when best-interests is forced to resort to something which is closer to 'necessity'. I realise that what I have just written is 'less than perfectly clear' but this isn't the place, for an in-depth elaboration.

Doctors really struggle with this – I could explain further, but I want to keep this piece short, so I will simply state that it is a really serious problem, when doctors look at the MCA.

3) Clinicians have things 'thrust upon them' which are not fundamental concepts within the MCA, and which are an unhappy and often contradictory fit with the MCA: notably 'safeguarding' and 'audit';

This is obvious, as soon as you think about it – a London GP was explicit about it, in an e-mail to me when we were swapping some e-mails about the MCA a few years ago:

'I recently had MCA training and it was made clear that the hope of the act was that it would be empowering of the patient and perhaps the development of the IMCA role demonstrates that aspiration.

We also have the whole 'safeguarding' agenda pushing in the opposite direction.'

Both a palliative care consultant I discuss EoL/MCA/CPR with and I, are vexed that if a patient on a ward makes it crystal clear to the nurses that 'I am definitely refusing attempted CPR from now on', if the patient arrests before the nurses can find a doctor to get various bits of paperwork completed, it is almost certain that the nurses would attempt CPR. As the doctor said in an e-mail:

'When the doctor explains to nurses '... but you are assaulting the patient!' the nurses tell him '... its all right for you – but we know what has happened to other nurses who withheld CPR in that situation, we need our jobs and we aren't willing to take the risk of withholding CPR'.'

There are similar problems, if a person tries to exercise the legal right to forbid 999 paramedics from attempting CPR if you are at home and were relatively healthy before you 'suddenly arrested'.

Even if we all agreed about what the MCA 'says', NHS clinicians are drowning under a flood of paperwork and their behaviour is 'audited' - so far as I can see, while this might not be too much of a problem if you are a patient in hospital and your interaction is with a consultant doctor, it is much more problematic for interactions with 999 staff in the patient's home.

One place where this can be seen, is the way that almost all CPR protocols require an Advance Decision refusing CPR (a legally-binding document which is signed by the patient but not necessarily by a doctor) to be 'turned into' a DNACPR form (not a legally binding document, but signed by a doctor and not by the patient): 'the NHS likes the DNACPR form because it is signed by a doctor' - despite this being 'legally perverse' in terms of the legal authority of the two documents.

4) Even if everyone agreed about what the MCA says [and currently that agreement does not exist], there would still be huge issues rising from 'perspective differences'.

It is not easy to separate this section from the previous one – many things could fit in either.

But, I will point out that even if everyone agreed about what the MCA says, front-line behaviour and professional mindsets are still influenced by the role of the person: one way of expressing this, is that 'objectives influence the order-of-importance which you attach to competing principles'. It is also true, for similar reasons, that different people 'see different things even when they are looking at the same situation'. The same factors apply, of

course, to people such as relatives who are involved – the main difference being that professionals will tend towards similar thinking more than laymen (I mean ‘999 paramedics will as a group tend towards having ‘a common mindset’’: nurses who work in dementia care will also tend to have ‘a common mindset’ - but, not the same mindset as 999 paramedics; etc).

To Close

I probably have not explained this very well, and I deliberately avoided including many links because I wanted it to flow when read.

But if a reader wants to find some of my other pieces, which do often include ‘references’, then I have many pieces and downloadable PDFs on Dignity in Care at:

<https://www.dignityincare.org.uk/Discuss-and-debate/>

I have recently tended to post PDFs in the thread at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mike-Stones-PDFs-I-hope-to-post-various-PDFs-about-EoLMCACPR-in-this-thread/944/>

I have recently written a ‘booklet of my thoughts about end-of-life’ (note – you want the second download, of version 2) at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Attached-is-a-PDF-containing-some-of-my-thoughts-about-End-of-Life-a-PDF-bookbooklet/983/>

And I put ‘useful court rulings’ and links to the rulings in my thread at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/SOME-COURT-CASES-RELEVANT-TO-THE-MENTAL-CAPACITY-ACT-and-to-BEST-INTERESTS-DECISION-MAKING/907/>

Closer to my heart at present – I have a thread within which I put my objections to ‘ReSPECT’ at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-issue-with-ReSPECT-which-I-will-be-pointing-out-to-the-Public-Guardian/960/>

Written by Mike Stone, May 2018.

mhsatstokelib@yahoo.co.uk

@MikeStone2_EoL

