

An Interesting Sentence

Some researchers at the University of Warwick, have investigated the use and effects of ‘ReSPECT’, and videos summarising their findings can be found at:

<https://warwick.ac.uk/fac/sci/med/research/ctu/trials/respect/results/event/>

There are two interesting sentences, in the video by Professors Slowther and Griffiths. This sentence (I’ll call this sentence no 1) is spoken:

‘Knowing the patient’s wishes also made relatives feel more confident in situations where they were required to share information on the patient’s behalf’

While we can hear that sentence being spoken, we can see a sentence (sentence no 2) written on the video-slide:

‘Knowing the patient’s wishes also made relatives feel more confident in situations where they were required to act on the patient’s behalf’

Sentence no 1 is interesting. Where does ‘required’ come from? What ‘authority’ requires the relative, to share information? I think the answer is ‘there is no such authority’ - so, it should probably be ‘when relatives are requested to’. And, standing as the relative, an obvious point is ‘why aren’t you asking my loved-one (the patient)?’. And a second obvious point, involves the ‘nature of’ the information being sought: it clearly cannot be ‘clinical information’, because the relative is not the clinician in this conversation.

The relatives [and close friends] should only be asked for ‘information’ if the patient lacks the capacity to make and express her own decisions about treatments – while capacitous, patients simply consent to or refuse offered treatments.

So, the sentence (if we are in England or Wales) must pertain to Mental Capacity Act best-interests decision-making. Someone (I’ll explore who shortly) must be attempting to apply section 4 of the MCA. The ‘information’ must be those things in section 4(6) of the MCA:

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.

We can now revisit that word 'required', with an understanding that the close friends and close relatives of the patient are the people who are likely to understand the things mentioned in section 4(6). It is the correct application of section 4 of the MCA, that 'requires' this information from relatives – so, we can rewrite sentence 1 as:

'Knowing the patient's wishes also made relatives feel more confident in situations where they were required to share information to facilitate a best-interests determination'

Note, that sentence doesn't say who, if any specific individual, is making 'the' best-interests determination. And, so far as I can see, the clinicians are also 'required' to disclose information, about the patient's clinical situation, treatment options and prognoses, in order for a best-interests determination to be ['correctly'] made.

MCA Best Interests, stands-in for 'Informed Consent' when the patient lacks the capacity to make his or her own decision. Almost always, I could only use my understanding of my loved-one, to answer a question phrased as 'If we did this to your dad, the outcome would be, or, if we did this to your dad, the outcome would be - so if we could ask you dad, what do you think he would decide?'

Actually, the MCA doesn't say who can make a best-interests determination. It appears that anyone who makes a determination and who could claim to have been sufficiently well-informed, could claim to have made a 'satisfactory' best-interests determination. I could go over ground I have covered elsewhere here, so instead I will point to pieces I have written previously in the Appendix.

However, it is worthwhile to consider who NEEDS the legal protection, offered by section 4 of the MCA. Often, that will be a clinician – for example, a surgeon. The MCA’s Code of Practice, using that reasoning, starts to ‘imply’ that it will normally be the clinician (usually a doctor) who determines MCA best interests. That is an over-simplification of the true situation: while a relative will not normally require the legal defences provided by ‘satisfaction of’ MCA 4(9), that does not mean a relative cannot arrive at an entirely legally-satisfactory best-interests determination. And, even if the doctor would be ‘doing the intervention’ (or not intervening), relatives who believed the doctor’s best-interests position was wrong could apply to the Court of Protection for a ruling.

It is not always true, that treatments are performed only by clinicians: cardiopulmonary resuscitation (CPR) is an obvious example of this – many lay people have been taught CPR as first-aid. See my blog in the Journal of Medical ethics:

<https://blogs.bmj.com/medical-ethics/2021/02/21/is-there-only-one-mental-capacity-act-or-are-there-two/>

A family-carer or friend would not be attempting life-saving heart surgery, or providing a life-saving blood transfusion: clearly clinicians will be doing that. But CPR is different – many relatives and friends could attempt CPR.

For CPR, if the patient is in hospital it will usually be clinicians who attempt, withhold, promote or attempt to prevent CPR – but, if the patient is at home, it will probably be family-carers who attempt, withhold, promote or attempt to prevent CPR. And anyone, clinician or relative, who wants to claim the legal protections in section 5 of the MCA needs to have ‘applied/satisfied’ section 4 of the MCA.

There is another ‘twist’ in the context of best interests and CPR – **the answer a relative or friend gives to ‘In this situation, would Fred want us to attempt CPR or would he refuse CPR?’ is a best-interests determination about CPR:** this follows, if the ‘Briggs’ ruling by Mr Justice Charles is applied to CPR.

In the Briggs case, the patient had gone from being capacitous to long-term comatose very quickly, and the judge had to decide if it would be in the patient's best interests to withdraw the CANH which was keeping him alive. The judge in effect decided that in such a situation, the MCA's Best Interests becomes a version of Substituted Judgement, which amounts to, using my words here:

If the decision-maker is satisfied to a sufficient degree of certainty that the patient would have refused the intervention 'had the patient been in the same situation but capacitous', then the intervention should be withdrawn or withheld,

and,

If the decision the patient would have made is not understood with sufficient certainty, then the treatment is continued or applied in an attempt to preserve the patient's life (and, of course, if it is believed that the patient would have wanted the treatment if the patient were capacitous to decide, then the treatment is also continued or applied).

As I pointed out above:

For CPR, if the patient is in hospital it will usually be clinicians who attempt, withhold, promote or attempt to prevent CPR – but, if the patient is at home, it will probably be family-carers who attempt, withhold, promote or attempt to prevent CPR. And anyone, clinician or relative, who wants to claim the legal protections in section 5 of the MCA needs to have 'applied/satisfied' section 4 of the MCA.

This, when the patient is at home and only a family-carer is present, fits with sentence no 2 from the video [although Professors Strowther and Griffiths might not have been thinking of the sentence in this context]:

'Knowing the patient's wishes also made relatives feel more confident in situations where they were required to act on the patient's behalf'

So: if the patient is at home, it will probably be family-carers who attempt, withhold, promote or attempt to prevent CPR – it will probably be a relative who ‘acts’ in response to a loved-one’s cardiopulmonary arrest.

It is very clear, that in principle the best-interests framework of the MCA can be applied at the time of a cardiopulmonary arrest (CPA) – and that framework requires the consideration of **information**. The ReSPECT form, is not completed at the time of a CPA, although a person might subsequently read the form during a CPA. It isn’t at all obvious, where the idea of projecting-forwards ‘a recommendation’ comes from – as opposed to recording information on the form.

The main ReSPECT form, can be completed when a patient lacks mental capacity (for example, is unconscious) and it will probably have a ‘recommendation’ about CPR on it. That recommendation is written by a clinician – which I object to, if relatives and friends possess best-interests positions which are just as valid and legitimately-formed as the opinion of that signing clinician. And neither the clinician, nor family or friends, needs the legal protections offered by section 5 of the MCA when the form is being written: CPR is not being attempted or withheld, at the time the form is created (it would be a future reader of the form, such as a 999 paramedic, who would need the protections of section 5 – not the clinician(s), and if I get my way other layfolk, who create and sign the ReSPECT form).

When I consider section 4 of the MCA, and in particular CPR, then I arrive at this for CPR on a form:

It is surely logically the case, that **in the absence of an attorney or deputy with authority** over best-interests decision-making conferred by 6(6), after the discussions between the various parties involved in the ongoing care of an already incapacitous person, **there will often be a group of people** –loosely, I’ll here write ‘ a group composed of family and clinicians’ - **who can each individually say** ‘my decision would be ‘whatever’ - and I think I can claim to have made that decision in compliance with section 4(9)’

That situation is only clear, if all of that group believe the same recommendation would be in the patient’s best interests: but in such a situation, logically the most ‘compelling and legally defensible’ thing on the form, which would then be read by someone such as a 999 paramedic, would be along the lines of:

‘We the undersigned, have discussed whether it is likely to be in this patient’s best-interests for CPR to be attempted, and we hereby sign to confirm that we all believe that DNACPR is in the patient’s best interests – we also confirm that to the best of our knowledge, no sufficiently well-informed person has

expressed the opinion that attempted CPR would be in the patient's best interests'

SIGNED BY EVERYONE – family and clinicians.

My Closing Message

Taken from what I have already written above, my summary message to both the creators of 'ReSPECT' and to anyone who is 'evaluating ReSPECT' would be these two points – and the conflict between the truth of these and the implication carried by the current ReSPECT form 'that what counts is the signature of a clinician':

For CPR, if the patient is in hospital it will usually be clinicians who attempt, withhold, promote or attempt to prevent CPR – but, if the patient is at home, it will probably be family-carers who attempt, withhold, promote or attempt to prevent CPR. And anyone, clinician or relative, who wants to claim the legal protections in section 5 of the MCA needs to have 'applied/satisfied' section 4 of the MCA.

It is surely logically the case, that in the absence of an attorney or deputy with authority over best-interests decision-making conferred by 6(6), after the discussions between the various parties involved in the ongoing care of an already incapacitous person, there will often be a group of people – loosely, I'll here write ' a group composed of family and clinicians' - who can each individually say 'my decision would be 'whatever' - and I think I can claim to have made that decision in compliance with section 4(9)'

Written by Mike Stone, November 2021

APPENDIX

These two pieces include discussion of MCA Best Interests:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/MCA-Best-Interests-compressed-to-a-single-sentence-an-ansatz/972/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/353/> (This piece, investigates [in view of the ‘Briggs’ ruling] MCA Best Interests for life-sustaining treatments)

This piece, investigates the law around ‘the documentation of a DNACPR decision in advance’:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/435/>

This piece, looks at the legal situation of a family-carer when a patient has a cardiopulmonary arrest at home:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/DNACPR-at-Home-and-a-Twitter-thread-what-is-the-legal-situation-for-relatives/1110/>

These two PDFs, give my comments on the current and previous versions of the ReSPECT form:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/420/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/296/>

And (from the thread 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/>) my ‘overall objections to’ the ReSPECT form are stated in this PDF:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/283/>

I recently contributed to a paper, and wrote a blog, published by the Journal of Medical Ethics, which considers CPR at home and the interaction between 999 paramedics and family-carers – my recent ‘follow-on’ piece here contains links to those two JME papers:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/>

I have also written about the interaction between 999 paramedics and relatives, in my thread at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-have-a-suggestion-for-how-family-carers-and-999-paramedics-could-be-reconciled-for-CPR-decision-making-feedback-from-family-carers-welcomed./1031/>

There is a really ‘nerdy and problematic’ issue around the verbal refusal of CPR:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Can-a-verbal-refusal-of-CPR-be-legally-binding/1072/>

And a similarly ‘vexing’ issue around the legal authority of a Welfare Attorney (or Court Deputy):

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Is-the-power-of-a-Welfare-Attorney-LPA-largely-an-illusion-a-response-to-39-Essex-Chambers/1103/>

And this piece explains where MCA best interests fits within ‘the process’ (The PDF explains that the best-interests decision-making described by the Mental Capacity Act to apply when a patient lacks the capacity to make his or her own decision about a medical intervention, replaces (or stands-in at) the stage when a patient with mental capacity would decide. So MCA Best Interests is NOT INVOLVED in the decision about what treatments are offered):

<https://www.dignityincare.org.uk/Discuss-and-debate/download/436/>