

My Twitter Poll – what are clinicians invited to do?

I mentioned a Twitter Poll in my earlier piece in this thread, and the Poll can be found at:

https://twitter.com/MikeStone2_EoL/status/919195401898680321

Before I move on to the results of the poll, and to an explanation of why I asked that particular question, I will introduce two of my e-mail exchanges.

In March 2015, I was exchanging some e-mails with Professor Bee Wee and one other person, and the following cropped up (it wasn't the main thing we were discussing). Bee is the NHS England lead for end-of-life – so she should be a well-informed source.

These are relevant the parts of the e-mails, from a single day:

Bee to me (11:21):

I agree with you that we need to break down the 'inappropriate separations' between the lay person and 'lived-with' person at home and professionals involved in the person's care - but along with that, there is a need to recognise that not everybody has live-with relatives that they trust. Obviously, in the many situations where they do, professionals do need to work with them as a team. In my own clinical experience, that happens a great deal, especially where staff have had a chance to get to know the person and those close to him/her.

Me to Bee (14:32):

'but along with that, there is a need to recognise that not everybody has live-with relatives that they trust. Obviously, in the many situations where they do, professionals do need to work with them as a team. In my own clinical experience, that happens a great deal, especially where staff have had a chance to get to know the person and those close to him/her.'

I agree with you - but the problem for EoL at home, is that in complicated and confused situations (an 'early patient death' for example, or an ADRT which 999 Paramedics do not already know about) the family and the paramedics/police 'do not know each other' and, logically, would never be able to 'know each other'. My issue has never been the way interactions with senior professionals tend to go (i.e. with GPs for EoL at home) but with what happens if family are interacting with only junior HCPs, and/or with police officers. I can assure you that arguing the toss around EoL issues with professors 'at leisure', is not the same as trying to get on the same wavelength with paramedics and police officers 'in stressful situations'.

Bee to me (this is the full e-mail) (15:18):

Absolutely agree with you Mike - no easy answers, sorry.

B

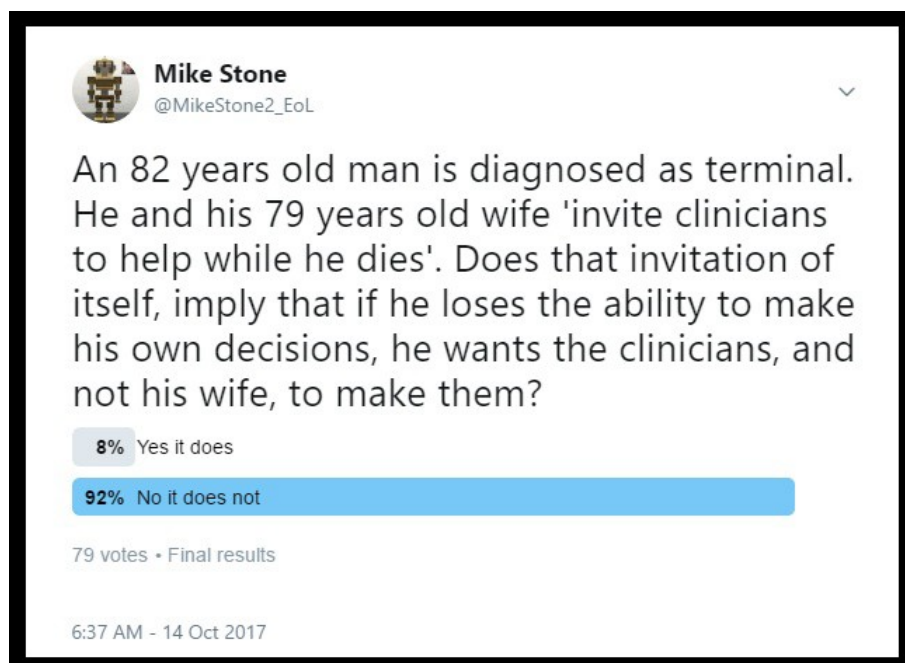
I will now quote from a different e-mail: this is extracted from an e-mail to me this February, from one of the senior clinicians who is a leading-light in 'ReSPECT' - I have added the bold text myself, to highlight parts of it:

*What you also need to realise is that the ReSPECT process is simply a summary of recommendations which reflect patient preferences about what might be clinically realistic in a future emergency situation. If the patient lacks capacity to engage with that conversation then **the guidance is very clear that those close to the patient must be consulted about what the patient's preferences might have been.** The clinician signs to say that they have followed correct capacity process and **that means discussing with those who know the patient best**, of course it does.*

The clinician who attends the patient during the emergency situation is the one who takes responsibility for the treatment and care decisions at that time so whatever information can be provided to rapidly inform them about realistic patient preferences is going to be helpful. ***This ReSPECT process is all about helping patients and families understand what is relevant and realistic for them and trying to give them more control over actions taken at a future time when a patient will be too unwell to make their wishes known.***

ReSPECT is asserting without any proof that 'the attending clinician consults the family carer who called 999, and then the clinician makes the decision' - I disagree with this assertion because it simply is **not** what our law, the Mental Capacity Act (MCA) states. But, before I move on to what the MCA says about 'decision-making and decision-makers', I will now introduce my Twitter Poll.

The Poll ran for 7 days, closing mid-afternoon on 21/10/2017. The poll appeared on Twitter like this (this is the way it appeared just after the voting had closed::



The poll closed with 79 votes, after it had been re-tweeted by a few people (I think by 4 people), with 8% voting 'Yes it does' and 92% voting 'No it does not'.

I opened the poll on a Saturday: on the following Monday it was 34 votes with 9% yes and 91% no; on the Tuesday it was 68 votes with 7% yes and 93% no. I looked at the voting on every day except the Sunday [when I had no online access] and every time I checked, the voting was essentially where it closed. So, assuming that people did understand the question, we have:

8 per cent of people think 'the invitation from the man to help while he dies, implies that the man wants the clinicians, and not his wife, to make the decisions if he can no longer make them himself'

92 per cent of people think 'the invitation from the man to help while he dies, does not imply that he wants the clinicians, and not his wife, to make the decisions if he can no longer make them himself'.

The question is quite tricky to word – for reasons which will become clear, I was not asking 'who should make the decisions, if the man can no longer make the decisions himself'. **And, of course, it takes only a little thought to understand that I must be talking about 'consent' here** – whether or not the man can make his own decisions, those decisions are of the 'should a treatment happen or not' variety: decisions about 'how a blood transfusion is performed' always fall to the clinicians performing the transfusion – but we make our own decisions about whether to accept an offered blood transfusion, and 'best-interests decisions' which are made after the man has lost his capacity, are similar (you can think of best-interests as the replacement for consent, when the patient is unable to consent because of coma, severe dementia, delirium, etc).

So, returning to what the clinician who is one of the people at the top of ReSPECT wrote:

The clinician who attends the patient during the emergency situation is the one who takes responsibility for the treatment and care decisions at that time

is conflating two different types of decision (see my tweet(s) at https://twitter.com/MikeStone2_EoL/status/906073527236907009):

The first type of decision – and the first question to be answered – is ‘should a clinically-possible and potentially clinically-successful treatment be applied or withheld’.

The second type of decision, once it has been decided to apply a treatment, is ‘how the treatment is performed’.

The first one is decision-making which is covered by the Mental Capacity Act, and the second one amounts to ‘clinicians should be clinically competent’.

It is the first one – should the treatment be applied – which does not devolve to the clinician who is present: the MCA simply does not assert that, although it is somewhat intricate to untangle what the MCA does state. I will describe here, what the MCA appears to say on the matter, but in the interests of brevity instead of elaborating on the ‘proofs’ I will simply provide pointers to the relevant parts of the MCA.

A ‘thumbnail sketch’ of the MCA

Most people think of the MCA solely in terms of ‘it is about mental incapacity’ – well, it isn’t, it starts by explaining that people must be assumed to possess mental capacity {section 1(2)} and it then explains the process of Informed Consent in its section 3(1), which is sufficiently important [and so often ‘missed’] that I will reproduce it here:

3(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).

The MCA goes on to include two methods by which a mentally-capable person who anticipates future mental incapacity, can assert some control over future decision-making during such mental incapacity: the person can create Advance Decisions (which are instructions to be followed during future mental incapacity) and the person can arrange for someone of his own choosing to make the decisions during future mental incapacity (attorneys under the Lasting Powers of Attorney Act: see MCA sections 6(6) and 6(7)).

If a person is appointed to make the decisions about healthcare – I describe this person as a Welfare Attorney – it is important to understand that the welfare attorney can be, and is I think most likely to be, a ‘normal person who is neither clinically nor legally trained’: **it immediately follows** that whatever making satisfactory best-interests decisions involves, ‘normal lay people must be able to do that’.

The MCA never makes it clear how a best-interests decision-maker decides: instead, it gives some 'requirements' in section 4, and it explains how the decision-maker justifies the decision in section 4(9):

4(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

The main thing which a best-interests decision-maker is told to discover, amounts to – and this is now essentially not disputed, if it ever was disputed – 'what decision would the mentally-incapable person have made, if the person could have made the decision himself?'. **If you cannot claim to have answered that question, then in my opinion you cannot claim to be making 'a GENUINE best-interests decision'** - section 4(6) is **fundamental** to best-interests decision-making:

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.

The 'thrust of' the MCA, is to allow individuals to make their own decisions if they are not 'proven incapacitous', and, if the individual cannot make the decision because of mental incapacity, to make best-interests decisions which are very-much steered by 'the patient's individuality'.

So who is logically best-equipped to make best-interests decisions?

I have explained that:

1) normal people – a group which obviously includes family carers, and other relatives and friends – are capable of making best-interests decisions (in other words, capable of 'deciding if a treatment should be applied or withheld' as described in section 4 of the MCA);

2) if it is clear that 'the patient has already made it clear what should happen in this situation' then that decision should be respected: legally, it is only refusals which the patient can definitely make in this way (see MCA sections 24 – 26 and in particular think about section 25(4)(c)) but 'the ethos of patient autonomy' is clear;

I will now point out that:

3) the MCA does not define 'who can make which best-interests decisions': it imposes a requirement (compliance with 4(9) without breaching 6(6)) for 'defensibility of the person's decision' - and the defence is 'a satisfactory application of section 4'. Which, in turn, requires the decision-maker to

‘understand’ section 4(6), which amounts to ‘to understand the patient as an individual’.

4) This is a logical conclusion, which I published a few years ago in connection with decision-making for cardiopulmonary resuscitation, and which has recently been used by Mr Justice Charles in a case about clinically-assisted nutrition and hydration – I will express it as:

‘The default assumption when considering best-interests decisions about life-sustaining interventions is that preservation of life should be attempted – but, if it is sufficiently clear that the person would have refused the intervention, it should be withheld or withdrawn’.

CONCLUSION

If you put together those things, it seems clear that what equips a person to make the most-satisfactory type of decision – a ‘genuine best-interests decision which fully incorporates the person’s individuality’ – is ‘life-experience of the person/patient’. It is the person’s close family and close friends who possess that ‘life-experience of the patient’: and, during end-of-life at home, it is the ‘family carers’ who have the greatest opportunity to listen to decisions expressed by the patient, and also to gain an understanding of the conceptually vaguer ‘patient’s wishes and preferences’.

Without that ‘ongoing and close contact with the patient’ it is not possible to ‘understand with sufficient certainty that the patient would have refused the intervention’: the consequence is that if you leave decision-making to 999 or A&E clinicians, they ‘naturally default to preservation of life behaviour’.

That default behaviour, is surely ‘worse’ than ‘genuine best-interests decision-making which involved an understanding of the patient’s individuality’.

So, what is the justification, for the assertion made by so many clinicians, that a previously uninvolved clinician – such as a 999 paramedic called to a collapsed EoL patient by a family carer – is the person who should be making best-interests decisions? It seems more logical to suggest that the 999 paramedic should explain the clinical situation to the family carer, and then ask ‘you’ve been involved with the patient – what should we do?’.

Many clinicians argue that ‘some family carers might have bad intentions’, which is true: ‘some police officers might be taking bribes’ and ‘a GP might be another Harold Shipman’ are similarly true, but for some reason those ‘mights’ are never mentioned.

The truth is in my opinion simpler: most family carers are doing their best to support their loved-one, and especially during end-of-life most family carers are guided by a simple approach of ‘we should all be doing what my loved-one wants to happen’.

In any event, it is clear that the Mental Capacity Act imposes a legal duty on family carers to act in the patient's best-interests, and that family carers are capable of making satisfactory best-interests decisions [setting aside issues of 'panic', and similar]: my Twitter Poll seems to suggest that most dying patients do not expect that if they lose the capacity to make their own decisions, that the clinicians would be making best-interests decisions instead of their 'close family' making the best-interests decisions; **so where does the assertion made by ReSPECT and many other clinicians 'that the clinicians make the best-interests decisions' come from, and how is it justified?**

Footnote

The e-mail I mentioned near the start of this piece, from the clinician who is a major force within ReSPECT, also included this:

You know only too well the huge culture shift that is required in many, many areas to make something like this work for patients and families but that needs to come from the public as much as from healthcare professionals. This is a significant step in the right direction but no one is under any illusions that it is the entire solution.

My issue with ReSPECT (see my letter to the Office of the Public Guardian with a complaint about ReSPECT <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/>) is that **ReSPECT is NOT supporting** the necessary culture change: the culture change which we need, is for everyone supporting the patient to be working together. So family carers, close relatives and close friends bring their understanding of the patient as an individual; clinicians bring their understanding of the clinical situation; **and everyone needs to be working together to help the patient - which can only happen if we start from a position of 'trust'!**