First Do Not Insult: a suggestion for reconciling family-carers and 999 paramedics during end-of-life.

There has been a flurry of tweeting about various issues around cardiopulmonary resuscitation (CPR) on Twitter recently, which I think 'originated with' a recent paper by Dr Mark Taubert 'Cardiopulmonary resuscitation is leading a double life: are we giving it an alibi?'.

The tweeting covered many topics, including how should conversations proceed if the doctors believe that the clinical outcome of a CPR attempt would be very bad but the patient or the relatives 'insist that CPR should be attempted', and how patients who have decided to forbid CPR can try and ensure their decision is respected by clinicians.

'Uncertainty' has also cropped up, but it is the uncertainty within the patient or relatives, of the clinical consequences of attempted CPR: the question being 'is the patient adequately-informed - or has the patient failed to consider some things which would, if understood, have altered the patient's decision?'.

I have always been bothered by a different type of uncertainty, from my Family-Carer During End-of-Life at Home perspective: the 'inevitable uncertainty' which results from 'I wasn't there to listen'. The issue I examined with my Father and Son scenario: in essence, when a relative is saying to a 999 paramedic '... my dad explained to me yesterday evening that ...' and dad is now collapsed and unconscious - it isn't possible to prove the conversation took place, if you are the relative, *and it isn't possible to prove the conversation did not take place if you are the paramedic*.

In my view, it is incredibly insulting for paramedics, or anyone else, to imply that the conversation did not take place.

It was a Twitter exchange with Dr Kathryn Mannix, author of the much-praised book 'With the End in Mind', that provided me with a 'hook' on which to hang this piece:

Kathryn tweeted

Mike, doc has 'ethical duty' to ensure the decision isn't based on a misunderstanding that might entirely change the person's decision if explained. Patient has the right to make an illogical decision, of course, but we're not checking their logic, we're 'avoiding harm.'

I pointed to a piece I've written about law, ethics and 'whose ethics', and then I tweeted

I'm wondering Kathryn - what do YOU think the 'moral duty' is for family-carers, when 999 staff are doing something 'I know my mum would have refused!'.

and Kathryn tweeted

To lie across their beloved parent screaming 'Get away!' But in the moment, the confusion, the sadness, who would think to do so? I absolutely agree with you on this.

Now, the way such a difference of opinion between a family-carer and 999 paramedics 'plays out' might be influenced by who the family-carer is - it could be a frail 85 yrs-old wife, or a 17 stone 35 yrs-old rugby-playing husband, and that wasn't analysed in those tweets.

But - I don't like this type of 'open warfare' between family-carers and 999 paramedics: we [family-carers] call 999 for help, not for 'a war'.

I need to describe our law next - I'm just going to 'assert' it, and if anyone thinks I'm wrong, then check up on the law.

In essence, and assuming that the patient was mentally-capable before the 'collapse', then the most important thing to understand is 'what would the patient have decided, if somehow an unconscious patient in this clinical [and 'wider-life'] situation could have made the decision?'. Only if the answer to that question isn't 'discoverable' is 'preservation of life/best clinical outcomes' resorted to, as the fall-back decision.

That requires an understanding of the patient: family-carers will know the patient, will probably have been 'listening very hard to the patient', and even if the patient has not been explicit, might still 'have picked it up'. Mr Justice Hayden explained this very clearly:

53 If ever a court heard a holistic account of a man's character, life, talents and priorities it is this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation. I have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want.

Obviously, the newly-introduced 999 paramedic cannot understand the 'mind of' a collapsed patient, who they had never met before.

I will concentrate on decisions about CPR - which is where this discussion started. During some recent e-mail discussions of Dr Taubert's paper, a paramedic threw in:

'[if] CPR was not the reason I was called, was not what was requested, and what most certainly is not what was wanted by the family, and more often than not the patient themselves (says who – well the person who firstly called me, and secondly spent every

night in the company of said individual for the past 60 years – it must be assumed they know the deceased better than me! – having never met them before!!)'

How do we turn the obviously correct logic of that - '***it must be assumed they know the deceased better than me!***' - into acceptable behaviour, when the paramedics cannot be certain of the background?

Now, unfortunately, even if we trust everyone, and accept that all family-carers are acting 100% honestly, it doesn't follow that all family carers will agree about what the patient would have wanted to happen: often, the family-carers will all agree, but 'honest disagreements' are possible even within 'well-informed family-carers' **and must be accepted**. What **I cannot accept**, is the idea that a 999 paramedic can understand what is in the patient's best interests, better than the patient's close family and close friends.

How might this be joined together, applying my 'first do not insult' principle, **but also** respecting the situation of the 999 paramedics and the law's 'preservation of life' fall-back position? This is what I would suggest - I started to describe this sometime around 2014.

The paramedic, after describing the clinical situation, treatment options and prognoses, asks all of the carers present 'are you sure of what the patient would want us to do?' - so, for CPR that simplifies to 'do you know if he would want us to attempt CPR?'.

Then, the paramedic believes the answers [**by default**] assuming the carers are reasonably 'calm and composed', and:

If all of the carers say 'I know she wouldn't want CPR' then the paramedics DO NOT attempt CPR;

If some of the carers say 'I don't know' but one or more firmly say 'I know she wouldn't want CPR' then the paramedics do NOT attempt CPR (*this one is perhaps contentious - it requires debating: see the footnote*);

If all of the carers say 'I don't know' then the paramedics DO attempt CPR;

However many carers say 'I'm sure he wouldn't want CPR', **if even one carer** says 'I'm sure he would want CPR' then the paramedics DO attempt CPR.

Footnote: the premise, is that any family-carer who promptly and 'forcefully' says 'I'm sure my dad wouldn't want CPR' will have a good reason to say that – but not reasons which could be elaborated during an arrest beyond 'because he's made it clear to me!' - so, presented with such 'certainty' from one or more relatives, any other relatives who are only willing to say 'erm … I'm not sure' **are not refuting the assertion strongly enough**.

The first of those respects the family-carers 'by not insulting them' - and the final one respects the 'fall-back of preservation of life when things are uncertain' principle.

And, I myself would never say 'my dad wouldn't want CPR' unless I had a very firm understanding of that - quite why it should be assumed that relatives are likely to give 'firm answers' without 'certainty that they are right' puzzles me.

And: **this is much simpler for CPR** - it is much more difficult for things such as strokes in my opinion. You can be sure that 'CPR isn't wanted': either because your loved-one has made it very clear to you that CPR is not wanted, or because your loved one has made it clear 'I would now prefer to be dead'. It is probably also 'simple' for a refusal of blood transfusion made on religious grounds. **It isn't simple**, if it turns out your loved-one has collapsed, seems to have suffered a stroke, and the paramedic says 'looks like a stroke - might be dying, but might live on with a lot of clinical damage - if we don't treat he might die within minutes but he might not die, and he might live on with clinical damage which would be reduced if we did treat him'.

That level of certainty is in reality not 'making a best-interests decision during an arrest' – it is in fact the application of the patient's self-determination during the arrest. And although it seems clear that conceptually, if it were possible to 'consider a best-interests decision during an arrest' then that decision would in fact be the answer to 'would dad want CPR or not?', it is in reality unrealistic to expect genuine best-interests decision-making to be taking place during a cardiopulmonary arrest (CPA).

I have been publishing a DNACPR Justification Hierarchy based on the MCA's description of the law, the principle that 'only potentially-successful interventions should be offered' and logic – it can be found here on pages 30 and 31. The basic problem, is how do we reconcile the fact that family-carers are likely to fit in at justification no 4 – whereas 999 paramedics can only logically fit in at justification no 5. The resolution to that problem, is what I have been discussing so far, and my 'rules' as given above are my suggested resolution.

There is also another issue, which we patients and relatives need clarity on: it is the simple question 'will 999 paramedics believe what we tell them?'.

There was a tweet by Alice Hodkinson during the discussions:

So, should we limit CPR to 5minutes? Stop sooner than is generally done? What time frame? Recent Adrenalin study interesting for increasing poor survival.

I'll ask a slightly different question. Suppose a person at home, has considered the possibility of suffering a cardiopulmonary arrest, and possible irreversible brain damage because of oxygen starvation when his heart isn't beating and if CPR isn't being performed. Suppose this person creates an Advance Decision and its instruction is 'I refuse CPR unless my arrest was witnessed and someone can confirm that CPR is being started within 3 minutes of the start of my arrest'.

Is current 999 behaviour as simple as asking on arrival, having been made aware of the ADRT, 'did someone see him collapse – and did he collapse 3 minutes ago, or even more recently than that?' and, unless someone says 'yes – he collapsed about 2 minutes ago' the paramedics withholding CPR?

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