

A Little More About 'Talking about Death'

There are at least two questions, relevant to 'talking about the dying part':

- 1) Will the conversations take place at all;
- 2) Will the conversations be 'explicit' or 'implicit' if they do take place ?

Because of the general lack of understanding about 'death', especially death at home, and also because of the attractiveness to professionals of 'neat protocols', both questions are relevant.

My answer to the first one, is 'with better training for clinicians, more conversations will probably take place'.

But my answer to the second, is that many of those conversations, or interactions, will in reality be 'implicit' – and the recording and dissemination of 'implicitly arrived-at understanding' is challenging, and of doubtful utility: by doubtful utility, I mean that it is probably not possible to adequately explain the sheer 'subtlety' of these 'implicit exchanges' to anyone who wasn't involved, through records. Which isn't what most 'NHS protocols' imply: if you were a police officer reading clinical 'protocols', they would I'm sure 'look quite different (neater) from the reality [for EoL at home]'. And we all know – there have been enough recent examples of this – that what police say they do, and what enquiries discover they actually did, tends to differ.

When my mother was comatose and nearing death, I asked her GP 'What would you like me to do, if my mum dies' – but we both knew that wasn't an 'if' but was a 'when'.

When my very ill mother refused to take some prescriptions, and was in general resisting treatment, I wanted (or needed) to understand if that meant she wanted to be left alone to die: but what I asked her, was 'If you don't take the medicines and energy drinks, you will go to sleep and not wake up again. Is that what you want ?'.

I know of two instances, when the 'or we could not treat you, and you will die' option was explained to patients in hospital 'implicitly' (I'm not sure of percentages here – I myself, don't know of any cases when that conversation was explicit).

One of the people who told me of this 'implied 'or we could leave you to die'' conversation, tells me that at the time she wasn't unhappy about it, because she 'knew her mother understood what was going on'. But subsequently she says:

"I found it quite a comforting at the time that those words were used, but only

because I knew that my mum had capacity and understood the implicit message, in the same way that I did.

However, since her death I have wondered whether she should actually have been specifically told that by not providing any active treatment she would die in hospital, because I would not want this [implicit] approach to be used with someone who would not understand the nuances of the 'nice words'. My feelings of guilt were based on the fact that perhaps my mother hadn't realised the implications of what the doctor said and I should have asked for a more honest statement - what if she had in fact wanted to be treated or risk the operation, that would have been her choice."

I replied to that, with something that 'troubles' me about my own mum's death. My mum was 'terminally peacefully comatose' for about 4 days before she died, and I must admit that during that period (when rolling her, etc, produced absolutely no signs of any 'consciousness') I 'behaved as if she had already [for all real purposes] already died'. But a few years later, I was reading a book about army nursing, and a nurse recounted how an entire ward of coma patients, one-by-one joined in with a sing-song until an entire ward of comatose men was singing in unison: then, they all stopped singing.

If I had read that before my mum's death, I would probably have talked to her, while she was comatose: I don't think she was aware of anything while she was comatose, but there is now just a tiny doubt in my mind.

One of my friends, when we were discussing her dad's death by e-mail, explained about both an 'implicit discussion' and also something else – I'm sure this second type of complication, is pretty common (I'll italicise my friend's words):

I asked my friend, when the doctor asked her dad, did the doctor explain the clinical factors to him ?

Her answer: *She did not tell my Father what the consequences of his response would be - this was a case of her manner indicating to him what she was asking.*

My friend also told me this during our discussion:

(My question): Secondly, and ignoring any considerations of 'sensibilities', who do you think was most likely to 'understand your dad's feelings' – your brother and you, or his sisters ?

I'm biased - but I think I had the best understanding (even better than my brother although we were in agreement anyway). His sisters would have given a different response - but my feeling is that their response would have asked for what was best for them, rather than my father - i.e. keep him alive as long as possible to postpone their grief. And my father would have wanted not to

hurt anyone's feelings, so if John and I hadn't been around to give our opinion then he would have gone along with his sister's wishes.

She added this further information – this is what I was referring to, when I said 'I'm sure this second type of complication, is pretty common':

Here are some more factors that come into play where my family is concerned:

1. My father and his sisters were / are non-practising but privately believers in God – so my feeling is that they didn't / don't want to make decisions for themselves or anyone else about death – they wanted / want to leave it in God's hands.

2. My opinion about how my aunts might feel is coloured by watching their behaviour when my mother died (only about 9 months prior to my father); they didn't hold my mother in much high regard and didn't really care whether she lived or died but they could see it was upsetting my father so they kept telling him that she was looking better and said "where there's life there's hope". He decided to listen to them which made my job of preparing him for the end pretty much hopeless.

I'm sure readers will be 'getting the point' – so

Conclusions

Almost everyone, 'sees the problems facing me': it is very easy, for people to believe that their own position 'is the trickiest'. **That isn't true – everyone involved with end-of-life, is faced with challenges.**

But – and I have trouble explaining this to many clinicians – it is difficult to understand other people: being professionally involved, isn't like actually being a relative, for example. And it could be argued, that being an 'expert professional' can make you fail to see things – I exchanged e-mails with Mark Miodownik about this very point:

Dear Mark,

It rang bells loudly with me, when in The Life Scientific you mentioned 'not seeing the wood for the trees'.

I'm a layman who has become involved in end-of-life debate, and there are potentially many different types of professionals involved (doctors, nurses, paramedics, police, judges, etc) as well as patients and 'family'.

It has become clear to me, that many professionals not only concentrate on a single species of tree, but perhaps on 'just branches' or 'just leaves'. But some fundamental issues, can only be correctly and 'neutrally' analysed by

looking not at 'a tree' but at the wood as a whole: to do that, it isn't necessary to know which trees are Ash and which Oak, but you do need to be able to see the wood rather than 'just the leaves of Oak trees' ! For some reason, expertise with the leaves of Ash trees, sometimes makes it harder to see that over the other side of the wood, many trees are on fire,

Regards, Mike Stone

Dear Mike,

Many thanks for your email. We are in complete agreement, and I think that these issues will be the greatest challenge for the future in almost every aspect of life (and death).

I do hope you continue to fight for greater understanding of these issues.

All the best

Mark

Thanks Mark,

Can I use your e-mail, in my discussions and writing about end-of-life behaviour ?

I frequently find that it is necessary to discuss both profession/role-induced perspective variation, and profession/role-induced perception variation.

Getting everyone to understand the first of those [perspective] is quite hard; getting all professionals to accept the existence of the second [perception], is much harder; and trying to describe a solution to the problems created by the second [re things like protocol creation for end-of-life home deaths] is very difficult indeed,

Regards, Mike

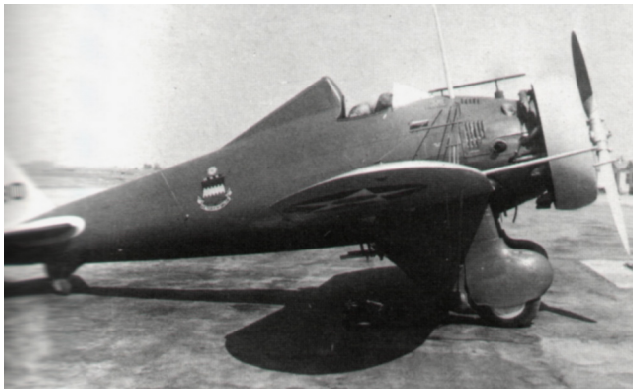
Sure, happy to be of some help.

Cheers

Mark

Things Change

This fighter aircraft, shown in the colour schemes of the US Army Air Force and also in the colour scheme of the US Marine Corps, was the USA's most advanced fighter in the mid 1930s.



To modern eyes this plane doesn't really look anything like a modern warplane - it looks much more like the type of aircraft which perform aerobatics at air shows.

Within 20 years, fighter aircraft had altered dramatically

(bottom picture) because of the development of the jet engine, and because of the necessity of solving the problems of compressibility which came with flight near to and above the speed of sound: the aircraft below, looks much more like a modern warplane.

The Mental Capacity Act DID CHANGE THINGS - but for some reason, the consequences of the MCA have not yet fed through as changes in clinical 'beliefs and behaviours', in the way that the jet engine prompted dramatic change in aircraft design.



The Consequences of Role-Induced Perception

I have mentioned, both perspective differences, and also perception differences in some of my writings: I wish to elaborate, on perception differences.

There is no doubt in my mind, that Perception Effects are hugely complicating, in end-of-life: they influence not only how different people 'see' the same physical event, but also how different people read the printed word.

Take, for example, section 25(4) of the Mental Capacity Act, which is describing the applicability of Advance Decisions:

- 25(4) An advance decision is not applicable to the treatment in question if—
- (a) that treatment is not the treatment specified in the advance decision,
 - (b) any circumstances specified in the advance decision are absent, or
 - (c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

I start from the position, that the purpose of a written Advance Decision, is to convey my decision to clinicians, if I have anticipated that I might at the time be mentally-incapable [and therefore unable to just tell them my decisions verbally, at the time of possible treatment]. I also don't see any 'shared decision-making here: I see it as an instruction from me.

To me, that follows necessarily, and in its entirety, from section 25(4)(c) - section 25 (4)(c), is saying that anything which I would have ignored when making my decision, isn't relevant: so, if 'whether my death could be certified or not' would not have affected my decision, that isn't something which can be used to disregard my ADRT; even a rider such as 'and this refusal still stands, even if my condition were caused by a murder attempt' would be possible, following 25(4)(c).

I have a particular issue, with how could I successfully refuse attempted CPR, if I arrested at home 'entirely unexpectedly'. The fact that one's heart stops beating unexpectedly, doesn't mean that the situation itself cannot be considered - I might decide that I would not want CPR if my heart had stopped beating for any reason whatever, if for example:

- a) I was elderly, I had started to show some early signs of becoming increasingly infirm, and a slow decline into really poor health held no appeal for me;
- b) I was still 'functionally relatively healthy', but I had been diagnosed with a

very nasty degenerative disease;

c) I had a particular 'fear' of 'being resuscitated but with significant brain damage' (perhaps due to oxygen starvation).

When I read sections 24 - 26 of the MCA, I see a law which says I should be able to achieve this, using a written ADRT.

However, 999 paramedics, seem to perceive different things, including:

d) A requirement that they should 'check the probity' of a [new and undocumented] ADRT - that alone, makes it impossible to refuse CPR for a 'sudden CPA' by means of a written ADRT;

e) Paramedics reverse section 1(2) of the MCA (the assumption of mental capacity) by asking, it appears, 'How do we know the patient was mentally-capable, when he created this ADRT ?';

f) They also 'throw in', it seems, doubts such as 'What would the Coroner make of my decision ?'.

The fundamental perception difference for end-of-life at home, concerns the position of live-with relatives (or family carers, whichever term you prefer to use). The question is, are they to be trusted by default, or not ? My answer is 'yes', but most professionals do not go straight to 'yes' - any answer except for 'yes' inhibits communication, promotes suspicion, and I would argue actually tends towards a negative feedback loop of less communication = more confusion = more suspicion = even less communication = even more confusion and suspicion, etc. And, it could be argued, that 'bad behaviour' is easier to detect, when discussion and communication is increased.

This perception issue, is very clear in something I posted online, but I will reproduce it all here as well (brown text):

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?forumID=45&obj=viewThread&threadID=705

06/10/13

13:01

Should the record of a conversation be 'Signed Off' by both parties ?

mike stone

There are some discussions, or conversations, between clinicians and laymen (patients or sometimes the relatives of patients) which are considered

so important that the clinicians are told to document the conversation.

The Independent Review of the Liverpool Care Pathway commented in its section 1.29 that 'the Review panel ... was also consistently shown, and all too frequently told of, instances where the form had been filled in wrongly - recording discussions with relatives or carers which they denied had taken place, or including observations that the relatives or carers believed had not been made. The Review panel appreciates that a record can only summarise the perspective of its author, and that a claim of false recording may be made because of a lack of clear communication between the clinician and the patient, relative or carer at a very difficult time for them'.

My question - I would appreciate some more comments about this - is, if a conversation is considered so 'important' that a clinical policy or protocol requires that the conversation be formally documented, then should the record of the conversation be shown to the layman, and 'signed off' by the layman, unless this is not possible for reasons of 'opportunity' ?

I originally phrased the question like this:

START

Now, I am aware to an extent of the various hierarchies, machinations and power struggles which afflict the NHS - but it seems obvious that if a 'protocol' considers it important that a conversation be documented, and bearing in mind that a conversation involves 2 sides, the documentation should if possible be 'signed off' by BOTH sides.

So if a hospital has a policy that 'a discussion about such-and-such with relatives should take place and be recorded', then unless something physical prevents this from happening, the note of the discussion should be read by whoever didn't write it (it would probably be written by a clinician) and then signed by that person. So a record of a conversation and its content, should be signed within the notes, by the clinician(s) and the layman(men).

This strikes me as blindingly obvious.

Clearly you can't do that with a phone call, at the time (and I'm not suggesting that all calls should be recorded): but lots of EoL interactions are ongoing, so there would be plenty of opportunity to show what has been recorded about things like conversations to the relatives involved, and to ask them to 'check you agree this happened' and to 'sign it off'.

It is clear that this is much less easy to achieve for electronic records, so probably this would need the retention of some written records: however, the Neuberger review seems to want written records for exactly this type of thing (sections 2.19 and 2.20).

This perhaps seems less obvious to 'the NHS', because the NHS likes clinicians, and in particular the senior medic, to 'control and sign off everything'.

END

I asked a layman, who I shall call 'Tim' here, and he came back with:

'Your logic certainly makes sense. All noted conversations should be signed off by both parties.'

I also asked a Civil Servant who came back with:

'I agree with the logic of both parties signing off conversations but I'm also concerned about the practicalities, and the effect it might have on relationships. If the end of life care experience for relatives becomes even more bureaucratic, or they get the impression that professionals are constantly acting defensively, that could be damaging to. It's a tricky one to balance, I think.'

So I went back to Tim, with:

'But I think being asked to confirm that a record of a conversation is correct, is exactly the opposite of 'defensive behaviour' by the clinicians - how about you ? I think more talking and especially more inclusiveness, would actually improve 'relationships'.

I don't actually want more bureaucracy, I'd like tighter integration between clinicians and laymen, and I suspect that if clinicians had to discuss more of what they had written with the laymen, it might concentrate their minds and get them to stop recording unnecessary stuff, and to record important stuff rather better ? But I'm not sure, about that.'

Tim came back to me with:

'100% agree with your take Mike. A double sign off does improve openness and also sharpens clinicians thought. There is no 'defensiveness'.'

Now, I exchanged e-mails for several years with the civil servant, and I exchanged a lot of e-mails with 'Tim' - I have no doubt at all, that they are both 'being honest in their answers'.

But Tim and I, see one thing as the more important (that records must be unambiguous, if examined in a dispute at a later time) whereas the civil servant sees something different.

I would add, that I see some potential problems with getting 'stressed laymen' to sign off these things - but I see the situations [and Tim is in such a position] when angry bereaved relatives become entangled in the equivalent of 'he says, she says' with NHS bodies, as being so unacceptable and damaging, that I support double sign-off as an objective in the same way that 'One Chance to Get it Right' supports 'more discussion' as an objective, and

the Tracey Ruling supports 'clinicians must tell laymen about DNACPR decisions' as an objective.

This makes discussions about end-of-life very difficult indeed:
some of these 'perception differences' are so deeply-ingrained, and so 'subconscious', that frequently 'people just can't see it'.

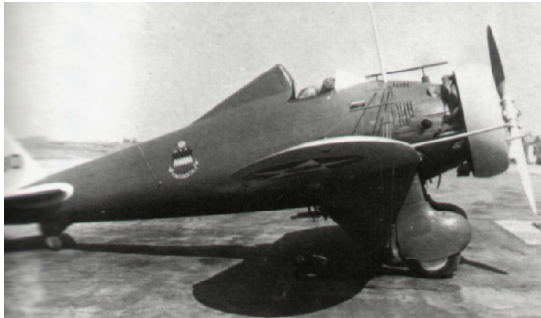
But to improve things, everyone must try:

'Walk My Journey'

'Walk Her Journey'

'Walk The Patient's Journey'

I Lied



I lied in my earlier piece - those two aircraft are not painted differently: in fact, they are painted with the same colour scheme.

We 'think' in terms of colour in our modern world, so if we see a black-and-white image, we 'sort of assume' that it 'is the same as the real world [colour] image, but without the colour' - we assume that the brightness of the greys, matches the 'brightness of the colours'.

But back in the 1930s, colour film was rare and expensive, and 'black and white' films simply did not do that: the shot on the left was taken using panchromatic film, and the one on the right used orthochromatic film. The different types of film, had differing sensitivities to reds, yellows and blues - so 'the film dramatically influences the record'.

When we were talking to a colour-blind friend at university, we made this mistake: we 'assumed' that he saw a world in which some things were coloured, but the colour he was colour-blind to 'came out as grey'.

He explained to us, that 'it is more like not seeing the things I'm colour-blind to at all'.

The crucial word is 'blind' - you can't see, what you are blind to.

So 'this little trick' was to reinforce my 'perception' point - different people, impose, inevitably, a 'projection' onto 'their view of the world and events in it'. A relative, a GP, a nurse and a police officer, might be involved in the same situation, but their perceptions of 'what is going on' (and crucially, of 'what is important here'), can be hugely different: but if two people are looking at a camel, and one believes it is a horse, it is still actually a camel.