

The words we use with the end in mind

I was prompted to write this piece, after the recent Royal College of Physicians [report](#) ‘Talking about dying’ recommended a book titled ‘With the end in mind’ by Dr Kathryn Mannix. I’m hoping to read the book courtesy of my city library, but probably not until December: the first chapter of Kathryn’s book is online (as a free-to-download PDF) [here](#). Dr Mannix apparently wrote the book for a lay audience, but the RCP report suggests that clinicians might read it to improve their understanding of end-of-life.

A couple of hours ago, someone tweeted to me a link to a report about frailty: and when I started to read it, I decided to steal its opening paragraph, because it describes something that I will be commenting on in this piece. The report is ‘**Frailty: Language and Perceptions** A report prepared by BritainThinks on behalf of Age UK and the British Geriatrics Society’ and it opens by telling readers this:

The term ‘frailty’ has many different meanings and applications. Age UK and the British Geriatrics Society (BGS) have identified how this varies amongst three key groups: geriatricians and other older people’s healthcare specialists, health care professionals without expertise in older people’s care and older people themselves.

Among older people’s specialists the term ‘frailty’ is used to describe a spectrum of physical and mental health states and is used to assess risk or to put together a care plan for an individual. By contrast, non-specialist healthcare professionals (HCPs), with less experience of older people’s care are thought to be more likely to use the term as shorthand for older people with complex care needs or in late old age.

I assume this problem – words meaning different things to different people – is generally common: it is certainly very widespread within end-of-life care and behaviour. For example:

End-of-Life is not used to mean the same thing by all people and authors – usually within clinical protocols it means ‘anticipated to die within the next 12 months’, but sometimes it means 6 months, and sometimes it means longer than 12 months (some people prefer Last Years of Life and so do I, but [LYoL](#) is very little used compared to EoL);

The terms ‘expected/unexpected/sudden death’ are used by clinicians and police officers, despite the fact that nobody has properly defined or analysed them: in fact the term ‘unexpected EoL death’ is deeply unsatisfactory. It could be done properly, as [I have pointed out](#);

Clinicians absolutely love the term ‘shared decision making’, but nobody can explain what that term indicates – as the influential [Realising Realistic Medicine](#) points out on its page 17 ‘While there is currently no agreed definition of shared decision-making in healthcare, ...’. See the text box, for what RRM stated and my issue with it:

While there is currently no agreed definition of shared decision-making in healthcare, the common variants used are all broadly similar in stressing the importance of people we care for and support and professionals working in partnership, making decisions based on the best clinical evidence, making sure that people are fully informed about risks and benefits, and combining this information with the person’s values and preferences.

My problem with this, is simple: it doesn’t make it clear ‘who in fact makes which decisions’. And not being clear about who makes a particular decision, is to be frank, a recipe for confusion and conflict.

That isn’t a clear description of either Informed Consent or (for England) of MCA Best Interests.

In the context of people who are entering the final few years of their lives, I suspect the next area of ‘terminological confusion’ will probably involve Advance Care Planning (ACP) – there are some obvious problems with the concept of ACP [which I have outlined](#), and the ‘solutions’ could well involve several different labels beyond any ‘catch-all’ label of ‘ACP’.

So, even when people do talk about end-of-life, it is very easy for conversations to be at cross-purposes, or, at least, for the various participants to leave a conversation with significantly different understandings of the conversation’s meaning.

Dr Mark Taubert wrote a [piece](#) about the RCP report, ‘Yes, doctors need to talk about dying, but what if patients started that conversation?’, and part of the paper is:

I spoke to our hospital’s patient and carer liaison group recently, and one of them was very clear that the societal taboo around this conversation may be decreasing. She felt that patients and their family members can be well placed to turn the tables on their doctor and ask the question themselves: “Can we talk about dying, Dr G?” I wonder what stereotypes doctors would fall into, and I suspect there might be a few shocked and silent practitioners.

Personally, I’m not convinced that it is easy to have that ‘conversation about the death’: it might be getting easier, but I don’t think it is easy. And I’m not sure about that ‘turning the tables’ language either, as an aside. During the ten years when I have been ‘involved in/with EoL debate’, since my [mother’s death](#), what I have noticed suggests that even when we do talk, we tend to ‘imply’ instead of being explicit. I will end this piece with something I’ve called Tina’s Story and an analysis of it: it was a real story that was told to me by the person I’m calling Tina here. But before I get to that story, I’ll point to two things which both happened about 10 years ago:

My own mother was comatose, at home, for about 4 days before she died, and after she had become comatose I said to her GP ‘what would you like me to do if my mum dies?’. Now – I knew my mum was going to die, and so did her GP: even so, I said ‘if’ instead of ‘when’;

The father of a friend of mine, died in hospital, and he was going to die - the question was how much intervention would he receive. He was mentally capable, and in theory the process of Informed Consent/Considered Refusal should have taken place. IN THEORY the doctor should have explained the clinical outcomes which would follow the choice (which was the removal of a catheter). So I asked my friend, when the doctor asked her dad, did the doctor explain the clinical factors to him? My friend’s answer: the doctor 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.

COMMENT: it is possible that now doctors are much more direct when they talk about dying, but I doubt it.

The rest of this piece is a description of another death, of the mother of the person I’m calling ‘Tina’ here. I talked to Tina face-to-face, and then we exchanged some e-mails, so I can use Tina’s actual words from her e-mails to me. Tina told me her own story, after I had told Tina about how the death of one of my aunts had led to a ‘falling out’ within my own family [that story doesn’t fit in with the theme of this piece, whereas Tina’s Story is a really clear and easy-to-grasp illustration of several end-of-life problems].

Tina's Story

I wrote [a piece](#) 'They Just Can't See It' about 3 years ago, and it started with a discussion of 'safeguarding', before a subsequent addition to the thread moved on to 'inevitable uncertainties' in an addition I titled 'WHAT CAN BE KNOWN ?' at 30/01/15.

That addition 'WHAT CAN BE KNOWN?' includes a description of what happened to someone I talked to a couple of years earlier – so it is a real story, 'trivially modified' to obscure the identity of the person. Here I will reproduce the online piece, which describes 'Tina's Story' and also discusses what it can tell us.

WHAT CAN BE KNOWN ?

Things which have happened, might be 'knowable'. But even some of these, are not 'knowable' 'universally'. If two people talk together, then one becomes unconscious before any record or dissemination of the conversation has been made, the only person who 'knows' about the conversation is the remaining conscious participant.

Records of past events, can exist and be read, but how does a reader 'know' the record is accurate ?

Things like 'the meaning of a multi-party discussion' can be disputed after the event by the participants: if there is a dispute about 'what the words meant', does anybody know what the words meant ?

Some present things, can also be 'unknowable' - in my end-of-life debates, police officers clearly 'want to know why a deceased person died', but often that simply isn't 'knowable' at the time.

Future events, are typically significantly 'unknowable'. Things such as the outcome of a cardiopulmonary resuscitation attempt, are so vague, that the term 'unknowable' fits them well. If you are aged 80, then the answer to 'will I be alive in 5 years time ?' isn't quite the same as if you are a healthy 20 yr old, and you ask yourself the same question.

There is also a problem, in that 'you can only know about, what you can see', where I'm using 'know' more in the sense of 'properly understand'. And people are 'perspective blind' to quite a lot, of 'what is in front of them'.

Why does any of this matter ?

In terms of my own 'stuff', mainly because the guidance currently being published, downplays 'uncertainty', and as a consequence would lead 'inexpert professionals' to fail to understand how complicated the real-world situations which other professionals are involved in, really are. For example, police officers are not routinely involved in end-of-life at home, but are involved sometimes: the 'theoretical situations and behaviour implied by current EoL guidance' which might be read by a [diligent] police officer, are nothing like as complicated as the real-world interactions between patients, GP, family and nurses.

I will recount a story I was told by someone, who I will call 'Tina' here.

TINA'S STORY

Tina's mum, who was in her 90s but 'fairly healthy', was rushed into hospital - the problem was both sudden and acute, and it would probably be fatal if left untreated. The doctor - I'll call him 'Dr Jones' - told Tina's mum (Tina was present), that there were two options. They could try to operate, but the surgeon thought she would not survive the operation - mum didn't fancy that. Or, he could do nothing - an option which he presented as 'Or we could just do nothing, and make you comfortable - but if you chose that, you will never leave this hospital'.

Mum went for the 'no active intervention' option, and died a week or two later.

One of Tina's sisters, who lived in a different part of the country, turned up at the hospital the next day. The sister wasn't happy, and wanted her mum to be actively treated - Dr Jones said 'it is now too late to attempt active treatment'. The sister then accused Tina - who, because she lived closest to her mum, was the sibling 'supporting her mum day-to-day' - of 'selfishly wanting our mum to die, because you are fed up of caring for her' (my phrase - but 'makes the point' here). Tina and the sister are no longer on speaking terms - and Tina has not explained this row to various other relatives, so she doesn't really like 'talking about her mum's death 'openly'".

Tina also has - looking back - another issue. At the time, Tina knew that the doctor's 'but if you choose that, you will never leave the hospital' meant 'if you choose no active treatment, you will die': and AT THE TIME, Tina felt sure that her mum also understood that. But WITH HINDSIGHT, Tina 'isn't 100% certain' - so with hindsight, Tina thinks the doctor should have made it clear that 'no active treatment means you will die' to her mum, so that her mum definitely understood the choice she was making. What Tina sent to me (words copied directly from the e-mail) was:

'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 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.'

So what seemed like 'soft and 'kind' vague words from the doctor to her mum' at the time, now WITH HINDSIGHT 'leave Tina with an ongoing slight concern, that perhaps her mum didn't understand what the doctor meant'.

Mum was put on the Liverpool Care Pathway, which wasn't realised by Tina, until a family friend (who was a GP) worked that out, and told Tina.

This type of thing, is really problematic for end-of-life [especially for patients who are in their own homes]: almost nobody is keen to discuss the more 'emotive' things [such as the actual death itself] and consequently it is really easy to make false assumptions 'about why people are doing things'. You simply cannot have good joined-up patient support, if the situation is 'very information poor' -

and making assumptions in information-poor situations, is a recipe for really bad behavior.

So, 'who knows what' in Tina's Story ?

Mum: mum might have understood that by not having the operation, she was in effect choosing 'to die as comfortably as the hospital was willing to arrange' - but we don't know for certain. I suspect - but I can't be sure - that the medics didn't really want to operate not because (as some people would be suspicious of) of 'age discrimination', but because of what doctors call 'frailty' (a reduced ability to withstand stress, which is often found in very elderly people [even if 'they just outwardly look old, not ill']).

Tina: the interesting thing re Tina, is this 'with hindsight was I wrong to not make Dr Jones spell it out to mum' thing - that 'hindsight guilt' clearly affects Tina, but because (as is fairly typical of this type of 'around a death' thing) Tina 'doesn't really talk about it', I think it is almost certain that Dr Jones doesn't understand how his 'kind words at the time' approach, caused issues for Tina much later on, after mum had died.

Tina's sister: I don't for a minute, believe that Tina wanted her mum to die 'because the day-to-day support had become too burdensome' as her sister 'claimed'. I think Tina just wanted her mum to make her own [informed] decisions. Tina's sister couldn't have been at the discussion between Dr Jones and mum, because that discussion would have been very soon after admission, and Tina's sister lived too far away - so the fact that the sister cannot be sure of who exactly said what, is not the fault of Tina or Dr Jones. This isn't the same as when people could be present, but are 'excluded from being present' - deliberately excluding people, is very often a bad idea.

There is something, that this 'people like to be involved and to understand what is happening' point, raises about 'NHS behaviour'. The NHS, still seems to somehow want 'a single named relative as a contact point': it is as if the NHS, which has internally got 'hierarchical structures' which it builds into its 'behaviour', cannot really cope with the less formal and more ambiguous 'relationships' within family groups. That really does need to change - attempting to impose 'structure and hierarchy' onto family and friends, however convenient it would be for clinicians if such hierarchies existed, isn't a helpful thing to try and do. Asking (can we contact the family through one person) is one thing - but imposing (we [clinicians] are only going to talk to the family through 'Fred'), is quite another.

Written by Mike Stone November 2018

e-mail mhsatstokelib@yahoo.co.uk

Twitter @MikeStone2_EoL