Communications and Mental Health Issues

I wasn’t sure whether to write about this one: it is in my opinion important, but it is quite difficult to analyse. It is even more difficult, to ‘suggest an effective way out’.

A couple of weeks ago, I was part of a 4-way e-mail discussion [which I initiated] which also involved a well-known Palliative Care Consultant Doctor, a Senior Paramedic and another Doctor (the ReSPECT Lead for a CCG – so I think a GP). The consultant and the paramedic are contacts of long-standing, the other doctor ‘is a new contact’.

We were swapping e-mails over 2 or 3 days, the discussion was very interesting, and it ended with the consultant and myself suggesting that the paramedic should write a short [academic] paper, about the theme of the e-mail discussion.

Towards the end of that e-mail discussion, I opened an e-mail from a doctor who thinks it might be helpful for us to discuss something, and while I would prefer to do that by e-mail, the doctor wants to meet face-to-face: as that would involve at least one of us travelling some distance, I don’t really see that the advantages of meeting physically justify the effort. It was put to me, as one reason for the preference to meet up instead of using e-mails, that some people the doctor knows have been upset by e-mails I’ve sent to them – upset as in ‘mentally damaged’.

When I put that comment/suggestion to a well-known ‘campaigning relative’ who I also swap e-mails with, the person sent to me:

You are gaining a lot of respect for what you’ve been saying on Twitter - you are knowledgeable polite and persistent and come clinicians see that as a threat. All I can say is keep going Mike!

There is only one ‘me’: I must believe that my e-mails have upset some of the doctor’s colleagues if I’m told that, although it wasn’t my intention – ditto I’ve been upset by e-mails from various ‘NHS people’, and my own mental health has been damaged by some NHS behaviour [including ‘absurd e-mails’]. I’m not very ‘empathic’ and I think I’m ‘a bit Aspergerish’ - there could well be a distinct ‘clash of ‘personality’’ going on, with respect to who is upset by what.

Kate Masters, spent years trying to explain to doctors and nurses, why it so important that patients and relatives are told about ‘clinical DNACPR decisions’ - despite Kate being, in my opinion, far less ‘forthright’ than I am, it is clear that some doctors had really upset Kate, as the **extracts** I’ll show from a wonderful BMJ rapid response written by Kate reveal:

http://www.bmj.com/content/358/bmj.j3831/rr-10

To be fair to Dr McCartney, the theme in this article is not unique and many doctors agree with what she says, a fact that is supported by the number of Tweets and Re-tweets in agreement on Twitter. What has tipped me over the edge is that, in her BMJ response to my Twitter response, as an attempt to provide the history of the case, Dr McCartney selected only those passages from a very balanced legal judgment (in my opinion) that support the stance in her article. Rather than provide a platform for debate, this one-sided approach can stifle it, or inflame it.

I could respond with more passages, or dissect Dr McCartney's selection, but that is far removed from the collaborative work I have been doing for three years. However, there are a few points that need to be made.

I have spoken to, and worked with doctors for three years since the legal ruling – on and off Twitter - explaining why, in the current challenging healthcare landscape that offers many real barriers to this discussion, it is so important to families that it is offered, because of the choices and chances the discussion offers. I am continually told that dad's ruling has had unintended consequences, yet have consciously avoided criticising the misplaced blame that is constantly placed on the ruling, choosing instead to factually correct the misconceptions. Yet at every turn I see blame coming back at me in the form of articles such as this.

If doctors really think CPR and DNACPR is in a mess because of legal cases, or 'the media,' without any introspective thought or wanting to understand the evolution of how we have got here, then this argument will continue to rage, and the circular discussion will continue to revolve. I cannot make any further difference to this debate whilst doctors continue with this mindset. I am exhausted with it all.

In addition, a note to all doctors; if you want patients to be part of the solution to the issues you face (not just this CPR debate) you may have to reach into their (our) world a bit more, rather than expecting us to adapt to yours.

I decided to post a Poll on Twitter, to see whether patients and relatives think the user side of the NHS also 'has mental trauma inflicted on it' - the poll and the two answers to choose from, were as below, and I show the final results of the poll:

Is it fair to say, that some of the patients and relatives who formally complain to the NHS, subsequently get the impression that the NHS Complaints Process is deliberately designed to damage their mental health? Please retweet.

Yes 91%

No 9%

23 votes

I was very frustrated, and also considerably annoyed, by the process of raising a concern with my PCT, and subsequently complaining to the PHSO about the behaviour of the PCT, a few years ago. The details would take too long to explain, but those two 'complaints to the NHS' arguably 'damaged' my mental health: and the advice I would give to other people is 'make your second complaint, first!'. In the sense of 'you learn so much about 'the process' - and how much of a disadvantage you are at because you don't understand the process but the NHS side does – that by the time you get to the end of your first complaint, you realise you should have done it differently'. So, my answer to my poll question, would also be 'yes'.

What 'damages my mental health' - and this happens **a lot!** - is when I carefully construct a question, or a reasoned critique of a protocol or of some guidance, send it to the 'author', and receive a totally non-informative and 'evasive' so-called 'answer'. Often a critique of some published 'guidance' is, often very belatedly, responded to with an e-mail which points you at the very guidance you are arguing is legally or logically flawed: to be frank, that is infuriating.

It isn't the type of response that a senior doctor should be sending – as this e-mail exchange with a 'very senior palliative care doctor' demonstrates, it is perfectly possible to send much more acceptable [if still 'frustrating'] responses. This cropped up – actually, as an 'aside' - during a discussion of something else:

From me to the doctor – this starts by quoting (I've made that text green here) from the doctor's previous e-mail:

''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'.'

The doctor to me (this was the complete e-mail):

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

Obviously I wasn't happy, that the problem wasn't being resolved – **but I was made aware, that the doctor understood that the problem existed**. As a 'PS' - what I want is 'perspective-balanced and fair-to-everyone' answers, not 'easy' answers.

And in my experience, 'face-to-face' real-world interactions (standing next to each other and talking) with some doctors and nurses can also 'affect' your mental health. I've had the truly surreal experience of two nurses refusing to confirm they were part of a Community End-of-Life Team, despite the fact that about 4 ft behind them there was a photo of the team on the wall, and they were clearly in the photo (and, to boot, the same photo had been used in the publicity for an appearance at a public event by some members of the team). I've also had a Palliative Care Consultant, refusing to give a simple yes/no answer to 'is your Trust using the ReSPECT Form?': as that was 'my Trust' (potentially a Trust that could be treating me), surely I can legitimately expect an answer to that question!

The BMA/RCN/RC(UK) Joint CPR Guidance, and other material published by the RC(UK), the BMA, etc, frequently contain things that are so logically flawed, or ‘perspective biased’, that simply reading them ‘upsets my mind’.

There are many things that ‘can cause mental damage’: and for me, it usually isn’t the medium (e-mail, face-to-face, Twitter, ‘published guidance’, things said on TV or radio, etc) but the message, that is often ‘annoying to the point of being ‘traumatic’’.

I think many people who become ‘lay NHS campaigners’, such as Kate Masters and myself, become involved because we were really upset by ‘something bad and [in our view] wrong’ that has happened. The ‘bad thing’ has already damaged us – we don’t volunteer, we feel compelled to get involved because we don’t want similar things to happen to other patients and relatives in the future.

It is important to us, that the professionals do understand, that we were really upset – often ‘traumatised’ - by what happened. In my case, the behaviour that I found unacceptable, involved relatively ‘junior’ clinicians: and ‘relatively junior clinicians’ **are influenced by** ‘guidance’ written by senior clinicians. I make no apology, for the fact that I am very forthright if I come across consultant doctors writing that section 4 of the MCA gives doctors ‘legal powers to intervene’ instead of describing the situation correctly (section 4 imposes a legal duty, it does not give legal powers – and, if you cannot work that out for yourself, then you have no business writing guidance about the MCA). Ditto, my vexation will also be obvious, if I write to the author of guidance which seems to stray into ‘protecting the professionals at the expense of damaging family-carers and relatives’. If those authors ‘are upset by the points I make’, then I am not going to apologise about that: I’m engaging from the patient and family-carer perspective, and I don’t see that failing to make it clear to the professionals that we find some aspects of their behaviour and mindsets are unacceptable, is going to prompt change.

One woman I know, was really upset by things that happened in a hospital – **and, understandably to me, she couldn’t face entering that hospital again**. When she wanted to discuss things with the hospital, the hospital repeatedly **offered her meetings at the hospital**.

A few years ago, Dr Shyan Goh and I were exchanging what could be described as ‘very robust opposing views’ in a series of BMJ rapid responses at:

https://www.bmj.com/content/350/bmj.h1481/rapid-responses

I think that such ‘robust’ critiques, are probably relatively unusual between clinicians, and particularly between nurses. I don’t think I’m any more ‘forthright’ in my e-mails – which it seems upset some clinicians – than I was within those rapid responses. And not everyone, is upset by the ‘robustness’ - a retired GP, L Sam Lewis, commented:

https://www.bmj.com/content/350/bmj.h1481/rr-21

Neither Shyan Goh nor Michael Stone need apologise for their keen interest in ethics and Law. Their debate is well-informed, civilised, and is teaching me a lot. Like our NHS, let's keep it public !

I am not suggesting that clinicians and Trusts deliberately set out to ‘mentally damage’ lay people who have issues with the NHS, nor am I suggesting that ‘lay NHS campaigners’ deliberately set out to ‘mentally damage’ the professionals they interact with: I’m saying, that it seems to happen, both ways, and I’m not sure that it can be avoided.

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