

Advance Directives, Advance Decisions: Concept or Law?

During a recent discussion on Twitter, I was pointed at a paper discussing Advance Directives – you can find the paper at:

<http://www.bmj.com/bmj/section-pdf/186407?path=/bmj/339/7732/Analysis.full.pdf>

The paper is by Stephen Bonner and others, and is titled 'Are advance directives legally binding or simply the starting point for discussion on patients' best interests?' - it discusses the issues raised by the combination of an 'advance directive' and a 'clinical emergency', and this is a situation which bothers me in the context of refusals of cardiopulmonary resuscitation by people who are in their own homes.

The paper uses a 'scenario' to discuss various issues, and it has opinions [which it calls Commentaries] from various people – the commentary which seems to me to be the most legally-correct is by Sheila A M McLean. I am puzzled by the failure of McLean to use the term Advance Decision, but she does write quite early in her commentary:

'Confronted with a legally valid advance directive, medical staff in England and Wales are essentially bound to follow its terms if they are applicable to the circumstances since the passing of the Mental Capacity Act 2005. The act enshrines the concept of autonomy in statute, allowing individuals to choose to avoid a particular treatment that they would, for whatever reason, find unacceptable.'

Concept or Law

As McLean points out: the MCA has enshrined Advance Decisions in English law, and the MCA also 'defines the requirements for its Advance Decisions'.

That is beyond a general concept – it is translation of the concept.

When I was reading the paper, despite it apparently discussing a scenario set in England and after the MCA had become the law, at times it wasn't clear to me that people were discussing the law as defined within the MCA: at times, it seemed that the 'idea of' an advance directive, was being applied to the scenario. This, I think, is one of the problems I encounter, when I discuss the MCA with senior clinicians – I start from the MCA, but many clinicians already had ideas about 'advance directives' which were established before the MCA was enacted.

This becomes clear, when reading the final two pages of the paper – it references many papers which are dated from before the MCA became a law: laws effect change, and we should be arguing from the MCA itself, until the MCA is changed through further legislation or 'actually modified by a court ruling'. 'Concepts shape the drafting of the Act, but once drafted and enacted, the Act defines the law'.

I could write at some length, about the various arguments presented in the paper, but I will instead focus on this sentence from the paper:

'In both this and our case the reason for refusing treatment was an unacceptable quality of life'.

Now, almost all doctors, when looking at an Advance Decision, would like to understand 'why the treatment is being refused'. Many clinically-authored Advance Decision templates, require that the reasons for the refusal are given on the Advance Decision (ADRT). An advance directive, when considered 'as a concept', might 'require reasons to be given': **but the Advance Decision defined within the MCA does not require the reason for the refusal to be given.**

See my BMJ piece at:

<http://www.bmj.com/content/356/bmj.j1216/rr-4>

While a law defining the concept of an advance directive might require 'the reasons for the refusal to be given', the fact is the MCA does not – the MCA says this:

24(1) "Advance decision" means a decision made by a person ("P"), after he has reached 18 and when he has capacity to do so, that if—

*(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
(b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.*

And:

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.*

As I pointed out in that BMJ piece:

The wording of 25(4)(b) implies that an ADRT would forbid attempted CPR in all circumstances, if it simply stated 'I refuse cardiopulmonary resuscitation (CPR)' - because, there are no stated circumstances to be absent. In contrast, 'I refuse CPR in all circumstances' seems to fall foul of 25(4)(b), because the vast majority of 'all circumstances' are necessarily absent, for any given arrest. We laymen, urgently need to be told what EXACTLY we need to write on an Advance Decision, to indicate that our refusal is intended to be unrestricted.

Section 25(4)(c) is worth paying attention to. It amounts to 'if the person reading the ADRT and considering treatment, is aware of something the patient was unaware of, and it is reasonable to believe that this new factor would have caused the patient to accept the treatment, then the treatment can be applied'. Personally, I cannot see how any 999 paramedic - who cannot possibly 'know the patient' - can claim, whatever the paramedic thinks might be a 'new factor', to reasonably believe that this new factor would have changed the patient's mind: a person who 'knows the patient', such as a family carer or a relative, might be able to reasonably believe that some new factor would have changed the patient's mind. But 999 paramedics, or A&E clinicians - surely not, if they do not know

the patient well, then how can they use 25(4)(c) as a justification to ignore the refusal recorded on the ADRT ?

There are many things which the doctors, patients, family carers and nurses involved in end-of-life **might like to know** [and, I think, some things which many patients would not like to know, as it happens]: some of those things are in principle 'knowable' but in reality are typically often 'unknown', and some things are inherently 'unknowable' (why a person seems to have died 'unexpectedly' when there are no obvious signs of the death being unnatural, is essentially 'unknowable at the time': but police officers seem to be 'unhappy' that the question isn't answerable – and I am unhappy with the behaviour of police officers in situations of 'somewhat early end-of-life deaths').

But it goes beyond 'I would like to know' when clinicians seek to impose on Advance Decisions, requirements which the law does not impose: and **there is no requirement** (despite a flaw in the MCA's Code of Practice which implies there might be) **for an ADRT to explain why the treatment is being refused.**

I would also point the reader to my piece 'Is 'Soft Paternalism' an arcane process?: or 'don't tell us its our decision, until you don't agree with our decision!' at:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=904&forumID=45

I ended that piece, with the issue at the heart of the implementation or frustration of advance decisions/advance directives:

If mentally-capable patients are making their own decisions, 'the risk of the decision being followed must therefore rest with the patient'. This is something which needs to be accepted for written Advance Decisions - otherwise, if you anticipate a treatment which might be provided 'during an emergency' and you try to forbid the intervention by using a written Advance Decision, your ADRT simply doesn't work. This acceptance of 'the risk rests with the patient' is CRUCIAL for refusals of clinically-possible cardiopulmonary resuscitation (CPR) if you are in your own home - at the moment, you can in theory do that, but in reality you almost certainly can't.

As it said in that paper about advance directives:

'Our patient's directive did not help staff to treat her as she would have wished. She lived almost pain free for another 18 months with some reservations but no resentment over her management and unfortunately subsequently died in hospital in a manner which she had tried to avoid.'

However, the paper also wants to accede to the wishes of clinician's to understand 'why the patient is refusing', in its:

'Advance directives form an opportunity to plan for end of life care but are more likely to be followed if they are fully informed, are regularly revised, if their limitations are understood,

and if they are drafted to reflect motivations rather than specify clinical conditions or interventions.'

I am sure that is true – however, 'my motivations are my own – and my Advance Decision is my INSTRUCTION and it is not 'a negotiation': so the solution is to accept the MCA as it stands, and to accept that the risk of an Advance Decision being followed essentially rests with its author, and not somehow with its reader.