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CONVERSATIONS WITH CHARLES

Clinical freedom, patient autonomy and NICE

Clin Med 2006;6:425–6

The National Institute for Health and Clinical Excellence (NICE) has a difficult job to do in assessing effectiveness of treatments. This can only be made more difficult if individual patients, or doctors treating them, challenge these decisions. The extent to which they should do so has profound ethical and practical implications. I asked Charles when such challenges were legitimate and got an unequivocal response.

'Never!' *was his reply, but anticipating my surprise he continued,* **'I am taking a narrow view of the question, but nevertheless the one that applies to the majority of cases.'**

'In doing so, what assumptions are you making?' *I asked.*

'I am assuming that NICE has given clear guidelines excluding the treatment requested. The patient has accepted treatment within the NHS. The doctor is working in the same system and is seeking not to follow that guidance during the treatment of that specific patient.'

'But that restricts their autonomy and clinical freedom!' *I replied.*

'Even in these days of the cult of the individual, autonomy can never be absolute. We still have criminal laws and civil laws which restrict our freedom, more of the latter than ever before! The individual must have the humility to defer to the collective good at the expense of his autonomy. The necessary rationing within the NHS is a prime example. Both patient and doctor implicitly accept this when treatment is within the NHS.'

'But Charles, the doctor's duty is to do the best for his patient!' *I protested.*

'Yes, but within the system in which he works. He does not provide the resources, nor does the patient directly. Both should remember NICE's assessment is as thorough as it can be. Individual lobbying often presents relative benefit as absolute thus exaggerating the potential value in the mind of the patient, causing great distress when the treatment is withheld.'

'Recently the Court of Appeal disagreed with you, Charles,' *I responded.*

'Not if you read the judgment carefully, Coe. The grounds on which the woman succeeded in challenging the decision to withhold treatment were not that NICE was wrong in their guidance but that the provider was inconsistent in their application.'

'What difference does that make, Charles?'

'The Court found that the provider was inconsistent in not allowing the therapy to the appellant whilst allowing it to women with small children. If the treatment was worthwhile for the latter, why not for the former? To withhold on those grounds was against her human rights.

I must say that I agree with the Court in this particular instance.'

'Are you suggesting that rationing should be based solely on the needs of the individual?'

'No,' *he replied,* **'I have always held that where there is a conflict between equity and "ageism" the former should prevail. This does not always work one way as I believe was suggested more than ten years ago in your College's Journal.[1] On the one hand, disproportionate resources might be accorded to ensure comfort in the last days of life, but on the other, where resources are scarce, preference should be given to those who have most to lose and therefore most to gain.'**

'What's that to do with equity, Charles?'

'I will give you a non-financial example. Consider a father and son with genetic heart disease but who are both otherwise fit. They are difficult to match and a heart comes up for transplant. Surely equity demands that it should be given to the son who would not otherwise have the opportunity to bring up his young family as had his father?'

My immediate reaction was that Charles's answer was not consistent with his agreement with the Court's decision, so I asked him.

'No,' *he replied.* **'The difference is that NICE's present position is that the treatment is inappropriate for anyone with her clinical features. The Court found that if the funder disagreed, it had to be consistent in its application irrespective of other non-clinical factors.'**

'But surely that does not allow for any discretion on grounds of equity?' *I suggested.*

'Not quite,' *he replied.* **'The crux of the matter is that NICE says the treatment is inappropriate for everyone. I do not believe that that should preclude NICE from issuing guidance which takes into consideration cost per year of life gained or non-financial limitation of resources as in our example. However, it must be for NICE and not the funding bodies to set the framework. The Courts, particularly the European Court, might find otherwise on the point at issue but then I would disagree with them.'**

'But that is restricting local autonomy!'

'The old chestnut of "postcode prescribing"; the irreconcilable conflict of achieving equity through centralised control and local decision making.[2] In this case my feet are firmly in the centraliser's camp.'

'To return to the original point, you seem to suggest that this woman's challenge was acceptable. Why hers in particular?'

'Inasmuch as she succeeded, she was challenging the referee and not the rules. It is a proper function of courts to make and review decisions within the framework of regulations or guidance set by others, but not to determine them.'

'What about the development of common law, Charles?'

'That might be a legitimate exception peculiar to the English system, but with all other regulations it is important that Parliament or an appropriate body sets them. The more technical the matter the more true this is. The majority of challenges question NICE's judgement and not the probity of the decision, and so should not be made.'

'Surely that does not mean that the patient or his doctor should have no input into treatment policy, Charles?'

'No it does not, they should be free to lobby for change in the guidance taking whatever route they feel fit, be it directly or through pressure groups or their professional organisations, but that is not to say that they should seek to deviate from current practice. Be it statute law, cricket or the NHS, if you don't like the rules do your utmost to have them changed, but life can proceed smoothly only if you are willingly prepared to follow them till they are changed.'

'I see what you mean.'

'And in this instance, Coe, more willingness to accept these principles might lead to greater peace of mind and less suffering.'

Charles is clearly suggesting that patients and doctors should sometimes be prepared to forego some autonomy and clinical freedom, and accept the choices made by others on their behalf. I am not sure that I would go as far as he does, but is absolute choice and autonomy possible, and if it is, is it always in the best interests of everyone all of the time?

Coemgenus

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