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## At the coalface

# Unproven treatment in childhood oncology – how far should paediatricians co-operate?: Commentary

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### Author's abstract

*How should doctors respond to requests from parents of terminally ill children for unproven treatments to be tried? Here it is argued that doctors faced with difficult cases where (1) it is not obviously against a child's interests to undergo an unproven treatment and (2) provided the treatment does not draw extravagantly on NHS funds, it may be appropriate, though not necessarily obligatory, for doctors to comply. It is important to recognise that often there may not be 'the right response' – only alternative appropriate responses.*

Is this a sensible question to ask? Does it contain the unwarranted assumption that there must be 'the right thing to do' in each case? Is it not possible that while the doctors in the case reported acted appropriately, other doctors faced with the *very same case* might have acted differently yet still not inappropriately?

Morality, after all, is not totally and pervasively directive. Often it sets boundaries to what we may do 'Not *that way!*' – without singling out a specific course as *the way*. Patients' rights, their relatives' rights, set boundaries to what doctors may do for their patients – for example, the need to obtain consent. But the general duty doctors have to serve their patients' interests is open-ended and non-specific. Thus it is possible that two doctors might respond differently to the same case though both were acting in accordance with this duty.

So as to avoid any presumption that there has to be just one way to handle a case such as that reported by Drs Yeoh *et al*, let us recast the question we want to consider as: 'Was this case handled *appropriately?*' We may further enquire what guidelines or considerations generally should be borne in mind by paediatricians when asked to co-operate in administering unproven therapies.

The problem paediatricians face when parents request their co-operation in trying unproven treatments is complicated in two ways: (1) the

unproven treatments are being chosen not by the patient but by proxies and (2) the administration of treatment is (partly) to be funded by the NHS. It might be helpful to start off by considering a simpler case, stripped of these complications, and then to return to considering the more complicated kind.

### The simpler case

Let us suppose that *you* are the patient with an inoperable cancer seeking your doctors' co-operation in the administration of an unproven therapy. You, we will suppose, are a competent adult without medical expertise, able and willing to pay in full for your own treatment. Your doctors have carefully and clearly explained to you their reservations about the therapy in question: having consulted with colleagues (oncologists and neurologists) they are convinced it will not cure and doubt that it will palliate. In addition to the obvious disadvantages attendant on operating on you they point out the risks relating to this procedure. All things considered they advise you against pursuing this therapy. But having heard them out you still want to go ahead. Indeed, if these doctors won't co-operate you'll seek out others who will.

In the circumstances what are your doctors' obligations – are they obliged to co-operate? Surely not. While you are within your rights taking risks with your own life and health, even foolish risks, others are not obliged to co-operate. If the risks you want to take are *patently* against your interests, then your doctors would be obliged to refuse to co-operate. They are, *qua* professionals, committed to using their skills only for their patients' benefit – that applies just as much to their private as to their NHS patients.

Suppose, though, that while the risks you would take in undergoing the unproven therapy are not patently against your interests, the considered view of your doctors is that the therapy is not worth a try, ie, is not *in* your interests yet, you disagree: are you entitled to insist, to demand, that they co-operate? It is uncontroversial that your doctors have a duty not to impose on you a treatment which you refuse but it is not so clear just what your doctors' responsibilities are in regard to treatments which you request of them.

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### Key words

Risks; parental rights; unreasonable requests.

Perhaps, we can agree at least that doctors have a duty to co-operate with any *reasonable* requests.

Such a duty, though, would only be *prima facie* binding: you may quite reasonably request a home visit of your doctor but if your request happens to coincide with a number of other similarly reasonable requests, your doctor may be unable, therefore, *not* obliged, to comply with them all. In the simple case we are considering there are no such impediments in the way of your doctors co-operating with you if they so choose. But *should* they choose? What you request is not obviously unreasonable, but nor is it obviously reasonable.

Are doctors only duty-bound to comply with requests that are *obviously* reasonable? Maybe so. After all, their professional status implies a commitment not just to serve their patients' wishes but to do so in ways that 'do no harm': *qua* professionals they are bound to take on board the interests of those they serve – unlike traders or craftsmen who are not 'unethical' in trying to drive a hard bargain and who have to respect customers' rights but do not have to worry about their welfare as such. Doctors, then, are not *automatically* obliged to co-operate in trying an unproven therapy just because the therapy is not obviously unreasonable and the patient can pay for it.

Even where doctors are not *obliged* to co-operate, they must consider all the same, whether co-operation in a given case is appropriate. Reasonableness, after all, admits of degree. Various considerations are relevant here. The possibility, for instance, that the patient might gain some individual benefit from the therapy proposed (Drs Yeoh *et al* note the possibility that inserting a central venous line in their patient could help with the terminal care). Also, it would be significant to establish *why* the therapy in question is still unproven; why has it not been adequately tested: is it because few researchers consider that the theory behind it has initial plausibility, or is it that the drugs concerned are expensive to produce or, that few appropriate subjects have been found on whom to test the therapy?

While doctors may not be automatically *obliged* to co-operate in trying out unproven therapies even if the patients requesting them (1) are not being obviously unreasonable and (2) are able to pay, there should, all the same, I suggest, be a *presumption* in favour of co-operating at least with patients who are desperately ill. Why such a presumption? For people who are desperately ill, whose power over the course of their own lives is suddenly and drastically reduced to be allowed at least the power of choice over what treatment to try – provided that choice is not crazy, would seem to be very much in their interests – even if in exercising this power they end up making choices which are not obviously reasonable, choices that their doctors think *they* would not make were their roles reversed. I suggest, then, that in the

'simpler case' we are considering here, the doctors may not be obliged to co-operate, but still their co-operating would seem *on the face of it* to be appropriate *and* their refusal to do so, inappropriate.

### The complex case

We have already noted that patients are not entitled to dictate, only to request, an unproven therapy. The same obviously holds for proxies: they can request but not dictate. Of course paediatricians owe parents information and advice so as to enable them to exercise their right at least to request. If parents upon being informed then request treatment which is clearly against their child's interests, doctors must refuse to co-operate. The doctors' primary responsibility is always to the patient and the rights of proxies to decide for patients are never absolute.

Much more difficult, of course, is the Drs Yeoh *et al* kind of case, where it is far from clear what *is* in the patients' best interests. Drs Yeoh *et al* say: 'It was very difficult to assess objectively the possible benefit of the proposed treatment'.

Is this another case where we may find ourselves struggling to answer a question which it is not sensible to ask, viz whether from an objective standpoint the unproven treatment is worth trying? What is the objective standpoint supposed to be? What it is worthwhile to try, surely, has to be in relation to someone's goals, interests, purposes. Trying an unproven treatment may not be worthwhile from a researcher's standpoint – not likely, perhaps, to attract funding, given the track record of the research already done, yet worthwhile from a terminally ill parent's standpoint if nothing better is on offer. Thus doctors *qua* scientists may rightly be sceptical about the worthwhileness of an unproven therapy yet if, like the parents, they are *simply* concerned with what is in the child's best interests they might agree that anything is worth a try which conceivably might palliate or prolong life – at least provided the cost of trying to the child is relatively insignificant.

Yet should the doctors who advise the parents and are responsible for the child's treatment consider simply the *child's* interests – or are their responsibilities importantly different from the parents', seeing that the treatment would be funded (partly) by the NHS? Thus, consider the question: How much is it reasonable to spend on a treatment which *might* save your child's life but probably won't? Another silly question, is it not? It all depends – we want to know, reasonable *for whom* to spend – for you? For me? For the NHS? Quite probably, there will be three different answers here. Hence, similarly, we should not assume that what the parents acting as proxies consider reasonable expenditure will be considered so by hospital administrators.

Just whose side should the doctors be on where the expense of an unproven treatment is considerable? Luckily, we do not have to answer that

question in regard to the Drs Yeoh *et al* case. I assume from the account given, in which the parents were shouldering much of the cost, the residual burden on the NHS would not have been thought excessive even by the hospital administration.

### The particular case (Drs Yeoh *et al*)

Did the doctors handle this particular case appropriately? I think so.

First of all notice that in this case it was not clearly against the child's interests to try the unproven therapy and yet neither was it clearly in the child's interests. Thus, the doctors were at pains to impress upon the parents their doubts about its efficacy and about the scientific credibility of the evidence for this therapy. This it was their duty to do, as the parents would not themselves be well positioned to appraise the reliability of the information they had received.

Yet when the parents indicated that they were determined to proceed in spite of the uncertainties and risks, the doctors deferred to their decision. This, too, was appropriate. Unless parents in such circumstances are *clearly* acting against their child's best interests, it is in the child's interests for doctors to comply with the parents' wishes. Why? Not because parents are better judges of their child's best interests in such circumstances but because the child is bound to suffer if parents and doctors are at loggerheads with one another (as, if parents are driven to seek out other doctors to take on the case). As Drs Yeoh *et al* say in defence of their decision to co-operate 'withdrawal of our care would leave the family in a much worse position'. Where the patient is a young child, its interests and the family's interests are interdependent – paediatricians have to care for the family for the child's sake. For the child's sake then, doctors should support the parents' decision – if they can, ie if so doing does not violate the child's rights or other people's.

In the Drs Yeoh *et al* case it does not seem that other people were wronged. NHS funds were not misused since the cost (I assume) was not high, the treatment tried was not obviously useless and refusal to co-operate with the parents was not in the child's interests. What about the child's rights? The child had a right not to be subjected to a treatment known to be useless and detrimental. The treatment in question was not known to be so, only suspected to be so. With the advantage of hindsight we may think that it would have been better had the parents admitted defeat. Certainly it would be wrong to suppose that for the terminally ill there can be nothing to lose in fighting on – fighting a battle that is already lost. All the same, at the time the choice was made it was not *obvious* the battle was lost, the choice the parents made for their child is one which some terminally ill competent adults would make for themselves in analogous circumstances. It was not therefore an inappropriate proxy choice.

Finally, does the presumption for which I have argued in favour of co-operating with the wishes of desperately ill patients transfer to their proxies? Maybe so. While Drs Yeoh *et al* were not obliged to attend to the parents' interests *as such* – they were not patients – we should expect the doctors as a matter of humanity to co-operate with the parents' wishes where they could, ie where in so doing they were not violating others' rights.

Thus, I conclude that although Drs Yeoh *et al* were not obliged to co-operate, they acted appropriately in doing so and, moreover, to have refused to co-operate in the circumstances of this particular case would on the face of it have been inappropriate.

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### Apology

The journal apologises to Dr Kath Melia, author of 'The task of nursing ethics', for transforming her name to Keith on the cover of the March 1994 issue.